

**- DRAFT -**

# Implementing a Comprehensive and Effective Community Response to HIV/AIDS in Communities of Color

*September 1, 2000*



**HIV/AIDS Health Disparities Work Group  
Department of Health and Human Services**

*Implementing a Comprehensive and Effective community Response to HIV/AIDS  
in Communities of Color*

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## ACKNOWLEDGMENTS

Policymakers face special challenges in formulating rational intervention strategies to address the growing complexities of the HIV/AIDS epidemic in the United States. Decisions must be made and policies implemented in a continually changing environment as the epidemic evolves and the development and refinement of diagnostic technology and medical therapy proceed. It is under these circumstances that this report, *Implementing a Comprehensive and Effective Community Response to HIV/AIDS in Communities of Color*, was written.

*Implementing a Comprehensive and Effective Community Response to HIV/AIDS in Communities of Color* reflects the efforts of a group of dedicated scientists, researchers, educators, and program staff representing a number of federal agencies. They worked diligently to develop this report while continuing to perform their daily duties of addressing the HIV/AIDS epidemic in this country. We acknowledge those individuals whose efforts made it possible to produce this comprehensive report.

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# *Implementing a Comprehensive and Effective Community Response to HIV/AIDS in Communities of Color*

## **EXECUTIVE SUMMARY AND RECOMMENDATIONS**

### ***Introduction***

In February 1998, when President Bill Clinton announced that the United States would commit to a national goal of eliminating racial and ethnic health disparities, the *Initiative to Eliminate Racial and Ethnic Disparities in Health* was born. The purpose of this national effort is to enhance efforts in 1) preventing disease, 2) promoting health, and 3) delivering care to racial and ethnic minority communities. The method consists of consultation and collaboration among federal agencies; State, local and tribal governments; and community professionals to research and address issues of education, environment, income, and other socioeconomic factors that affect health outcomes. The Initiative targets six key areas of health: infant mortality; cancer screening and management; cardiovascular disease; diabetes; HIV/AIDS; and adult and child vaccinations. This report focuses on the HIV/AIDS target area.

On March 3 and 4, 1998, the Centers for Disease Control and Prevention (CDC) sponsored a meeting with approximately 35 African American leaders working in the area of HIV prevention. The purpose was to refine CDC prevention efforts in African American communities. However, after hearing the statistics on the disproportionate impact of HIV/AIDS in the African American community, the leaders stopped the meeting, demanded to meet with CDC's Acting Director, and issued a list of nine demands. The most significant and urgent of these demands was the call that "(t)he President and Surgeon General declare a state of emergency in the African American community concerning AIDS and public health."

On June 10, 1998, several members of the Congressional Black Caucus (CBC) held a town hall meeting. The meeting was attended by over 100 participants including representatives from community organizations and members of the Executive Branch of the federal government. At the conclusion of the meeting, the CBC called on Secretary for the Department of Health and Human Services (DHHS), Donna Shalala, to declare a state of emergency around HIV/AIDS in the African American community. Over the next four months, DHHS actively considered this request. With extensive involvement by several members of the HIV/AIDS Health Disparities Work Group, DHHS prepared and presented a response to the Caucus in September 1998. In that response DHHS stated that a state of emergency would not be declared, but that the HIV epidemic in the African American community is a crisis requiring an emergency response. DHHS then directed the federal agencies to redirect some of their current efforts in fighting this disease. Given that some of these agencies were already leveraging fixed resources to increase aid to some communities of color, the order to redirect resources resulted in a modest response to the request.

Then in October 1998, President Clinton addressed the issue of HIV/AIDS specifically in a public address when he declared HIV/AIDS to be a severe and ongoing health crisis in racial and ethnic minority communities and announced a comprehensive new initiative in collaboration with the CBC to improve the nation's effectiveness in preventing and treating HIV/AIDS in communities of color. Redirected new funds totaling \$156 million in FY99 were appropriated to enhance the fight against HIV/AIDS in the African American community as well as in other communities of color. For FY 2000, this targeted funding was increased to \$251 million.

The DHHS Minority HIV/AIDS Initiative, as this enhanced response to HIV/AIDS in racial and ethnic minority communities has been named, is targeted toward: 1) technical assistance and infrastructure support;

2) increasing access to prevention and care; and 3) building stronger linkages to address the needs of specific populations.

### ***Epidemiology of HIV/AIDS in the United States***

HIV/AIDS has had a devastating effect in racial and ethnic minority communities. The threat of HIV/AIDS not only affects people who have the disease themselves, but also their families, loved ones, neighborhoods, and communities. Through December, 1999, more than one half (55%) of all identified cases since 1981 have been reported among people of color. The most heavily affected population has changed from non-Latino Whites to African Americans, and the proportion of cases reported among Latinos is growing. Each year, 74% of the estimated 40,000 annual HIV infections are among African Americans and Latinos. Priority sub-populations that pose the greatest need for effective interventions within communities of color are men of color who have sex with men, intravenous drug-users and their partners, women and youth of color.

### ***Underlying Causes of Health Disparities***

Racial and ethnic minority communities are among the fastest growing of all U.S. communities, yet African Americans, Latinos, American Indians and Alaska Natives, and Asians and Pacific Islanders have poorer health than other communities. The concept of health disparities was highlighted in the Department of Health and Human Services 1985 *Task Force on Black and Minority Health*. The task force detailed the widening disparities between minorities and nonminorities in six health areas: cancer, cirrhosis, diabetes, homicide, unintentional injuries, and infant mortality. In 1987, HIV/AIDS was added to this list. Underlying causes of health disparities are global in scope. Health disparities are influenced by multiple factors such as, socioeconomic status, education, availability of adequate health insurance, employment, racial/ethnic and cultural biases as well as political and societal attitudes, none of which on its own merit, can be singled out as the primary denominator.

### ***Components of an Effective and Comprehensive Community Response to HIV/AIDS***

Communities play an important role in preventing the spread of diseases. Community members bring knowledge about the community's culture, social norms, and networks, all of which can be used to better define health problems and devise solutions to them. Community-based organizations are taking positive approaches to health and well-being through planned, coordinated and sustained efforts. In the area of HIV/AIDS prevention and treatment, there is support and appreciation for the benefits of working in partnership with communities to promote health behaviors and to reduce risk factors associated with HIV transmission. The premise underlying community planning as the main vehicle for delivering prevention services at the local level rests on the importance of community. Identifying community assets, community participation, and effective collaborations and partnerships remains paramount for effective community responses to the devastation of HIV/AIDS in communities of color. Equally important are effective prevention programs that includes epidemiological and behavioral surveillance, voluntary HIV counseling, testing, referral, and partner notification, health education and risk-reduction activities, school based programs for youth, public information programs, and capacity building activities to support organizations in expanding their abilities to implement effective programs.

## ***Effective Interventions***

Biomedical and behavioral HIV prevention programs have proven to be effective in reducing HIV transmission. A reduction in mother-to-child transmission through taking AZT during pregnancy, for example, has proven to be an effective biomedical intervention as well as individuals benefitting from prophylaxis for opportunistic infections, combination drug therapies, and treating sexually transmitted diseases for prevention of HIV infection. Behavioral interventions can contribute to changes in behavior that reduce risks of infections as well. Some effective individual and community-level interventions around frequency of condom use includes role model stories developed from real-life experiences and behavior changes resulting from the effects of media campaigns, outreach, and community mobilization.

## ***Assessing Existing Services and Identifying Unmet Needs***

Agencies of the federal government have long recognized the importance of surveillance, education, research, prevention, and care as key components of a comprehensive effort to fight the HIV/AIDS epidemic. Responding to the shift in the populations most impacted by HIV/AIDS (i.e. communities of color), DHHS in partnership with Congress and the President have publicly recognized that HIV/AIDS is a severe and ongoing health crisis in racial and ethnic minority communities. The operating agencies of DHHS, which include, but are not limited to CDC, the Health Resources and Services Administration (HRSA), the National Institutes of Health (NIH), and the Substance Abuse and Mental Health Administration (SAMHSA) are continuing to enhance and target their HIV/AIDS activities to reach and target populations most severely impacted by HIV/AIDS.

## ***Recommendations***

Based on an inventory of HIV/AIDS activities currently underway within DHHS, 20 recommendations for enhanced and new activities to further address disparities among communities of color were developed. Some of the recommendations have been adapted from the draft “National Minority HIV Plan,” dated September 1998, developed by the DHHS Office of Minority Health. In addition, these recommendations have been categorized into six broad public health categories: 1) program; 2) program evaluation; 3) policy development; 4) research; 5) surveillance and epidemiology; and 6) technical assistance and capacity building.

The recommendations reflect only one piece of a national effort needed to eliminate HIV/AIDS health disparities among communities of color. Most of these recommendations reflect changes in or enhancement of activities which fall under the purview of DHHS. However, any movement toward refining or implementing the recommendations presented here will require the involvement of other federal agencies, community members, persons who are infected and affected by HIV/AIDS, national organizations, community-based organizations, and state and local representatives.

It is also crucial that programs, evaluation activities, policy development, surveillance, and research activities that arise as a result of these recommendations be developed in a culturally competent manner. Cultural competence may be defined as the capacity and skill to function effectively in environments that are culturally diverse and are composed of distinct elements and qualities. To be effective, all HIV/AIDS interven-

tions must be culturally competent. Cultural competence helps to ensure that prevention, research, and treatment programs are acceptable to the communities for whom the programs are intended. Cultural competence is **not** about the service provider's **sensitivity** to diverse cultural populations. Cultural competence **is about** the service provider's **understanding of and respect for** cultural differences and how a client's culture affects his or her beliefs, perceptions, attitudes and behaviors regarding HIV/AIDS.

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*Implementing a Comprehensive and Effective Community Response  
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**EPIDEMIOLOGY OF HIV/AIDS IN THE UNITED STATES**

***Introduction***

A majority of the data presented in this section of the report was taken from the HIV/AIDS Surveillance Report, December 1999, Year-end edition and slide sets which have been developed using some of the data in the report. The HIV/AIDS Surveillance Report and slide sets can be found at the CDC web site listed in Appendix B.

The disease that would come to be known as acquired immunodeficiency syndrome (AIDS) was first identified in the United States in 1981. As of December 31, 1999, a total of 733,374 AIDS cases among adults and adolescents and 8,718 cases among children under age 13 have been reported to CDC. More than 430,444 people of all ages have died.

AIDS has had a devastating effect in racial and ethnic minority communities, affecting not only people who have the disease themselves but also their families and loved ones. In 1998, people of color made up more than half (178,914) of the estimated number of people believed to be *living* with AIDS in this country (294,425). Through December 1999, well over half (55%) of all identified AIDS cases since 1981 have been reported among persons of color. Among children under the age of 13, African Americans represent 59% of all reported pediatric AIDS cases, and Latino children make up 23%. In 1999 alone, African American children represented an even larger proportion (65%) of pediatric AIDS cases reported that year.

Currently, an estimated 800,000 to 900,000 persons in the United States are living with human immunodeficiency virus (HIV) infection, including those persons with AIDS. Over the years, the predominant mode of HIV transmission has been shifting from male-to-male sex to heterosexual transmission and injection drug use. The most heavily affected population has changed as well, from non-Latino whites to African Americans, and the proportion of cases reported among Latinos is growing.

Confidential reports of HIV infection from the 32 states that have implemented HIV surveillance among adults and adolescents and 2 states that report only pediatric cases, show that communities of color are continuing to be the most heavily affected; cumulatively, 61% of reported HIV infections in these states have been reported among members of racial/ethnic minority groups. In 1999 alone, people of color represented 61% of newly reported cases of HIV infection in these states.

Each year, 74% of the estimated 40,000 annual HIV infections are among African Americans and Latinos. Approximately 22,000 African Americans and 8,000 Latinos are becoming infected with HIV each year. (This estimate is based on using indirect estimation methods based on national AIDS surveillance data and HIV surveillance data from states that have conducted HIV surveillance for at least five years.)

Many recent advances in the medical management of HIV disease have favorably affected the trends in AIDS incidence. The good news is that more people with HIV and AIDS are living longer. However, the resulting longer survival period also has resulted in growing numbers of people who require ongoing preven-



tion services and expensive medical care. The Presidential Initiative on Health Disparities was established to help ensure that all members of our society participate in those advances and reap the benefits of good health.

This chapter presents the epidemiology of HIV/AIDS to provide a context for understanding the dimensions of the impact of HIV/AIDS on communities of color. It includes estimates of the number and describes the characteristics of persons in the United States infected with HIV and of persons who have developed AIDS. Also, it addresses risk factors, presents the distribution of HIV and AIDS by route of transmission, and discusses related morbidity and mortality.

### ***HIV Transmission***

HIV infection is most commonly spread among adults through sexual intercourse (both homosexual and heterosexual) with an infected person. Also, many people who inject drugs have become infected by sharing needles or syringes that contain HIV-infected blood.

### **Men Who Have Sex with Men**

Sexual contact between men was first identified as a risk factor for AIDS early in the emerging epidemic. During 1989-1998, AIDS was diagnosed in 290,582 men who have sex with men (MSM). In 1989, racial/ethnic minority MSM accounted for 24,444 (31%) AIDS cases among MSM. The proportion of MSM with AIDS who were non-Hispanic black and Hispanic increased from 19% and 12%, respectively, in 1989, to 33% and 18%, respectively, in 1998. Asian/Pacific Islanders and American Indian/Alaska Natives each accounted for <2% of AIDS cases among MSM throughout this period. AIDS incidence among all MSM declined 22% from 1996 to 1997. The rate of decline slowed to 12% in 1998 compared with 1997. During 1996-1998, AIDS incidence declined among MSM in all racial/ethnic groups: Asian/Pacific Islander (43%), non-Hispanic white (39%), American Indian/Alaska Native (35%), Hispanic (26%), and non-Hispanic black (23%). Stigmatization of homosexuality in communities of color influences the availability of HIV/AIDS information and services as well as the willingness of persons to seek HIV testing and care and to disclose their seropositive status to partners.

### **Illicit Drug Use**

Drug users are at high risk of becoming infected with HIV by sharing injection equipment as well as through unprotected sexual activities, poor sanitary practices, under-utilization of health care, and frequent and risky interactions with persons who are already HIV infected, including prostitutes and injecting drug users. The impact of drug use as a risk factor for HIV infection has been substantial in communities of color.

### **Heterosexual Transmission**

No AIDS cases prior to 1982 were attributed to heterosexual contact. In contrast, among people reported with AIDS in 1999, 8% of men and 40% women reported they became infected with HIV through heterosexual exposure. Associated risky behaviors include having multiple sex partners; buying, selling, or trading sex; early initiation of sexual activity by adolescents; and unprotected sexual intercourse.

## **Perinatal HIV Transmission**

Almost all HIV-infected children in the United States acquired the virus from their mothers during pregnancy or birth; a few may have become infected after birth through breast feeding. Through December 1999, an estimated 8,718 AIDS cases have been diagnosed among infants and children younger than 13 years. Ninety-one percent of these infants have been infected perinatally. As of December 1999, an estimated 5,084 infants and children have died with AIDS. In 1994, clinical trials demonstrated a two-thirds reduction in the risk for perinatal (mother-to-infant) transmission associated with treatment of HIV-infected pregnant women and their infants with zidovudine (ZDV, also known as AZT). The Public Health Service (PHS) issued guidelines for the use of ZDV to reduce perinatal transmission in August 1994 and for universal HIV counseling and voluntary testing of pregnant women in July 1995. Since that time, there has been an increase in both HIV testing among pregnant women and the use of ZDV treatment among HIV-infected mothers and a steep decline in perinatally acquired AIDS. More recently, some of the decline in perinatal AIDS incidence can be ascribed to improved treatments which delay the onset of AIDS-defining illnesses for HIV-infected children. The rate of perinatal transmission is expected to continue declining as a result of more aggressive courses of treatment and increased use of procedures that reduce transmission during childbirth, such as elective cesarean section. Declines noted between 1992 and 1996 were similar by race/ethnicity and regions of the country and in both urban and rural areas.

## **Receipt of Blood Transfusion, Blood Components, or Tissue**

Through December 1999, 8,531 adults and adolescents and 379 children were reported to have acquired HIV infection through receipt of infected blood, blood components, or tissue. However, most of these infections were acquired during the early to mid-1980s. Since 1985, the Red Cross and other blood banks have routinely screened blood products for HIV, and the risk for HIV infection from blood transfusions has decreased greatly. Since screening was implemented, 37 adults and adolescents and 2 children developed AIDS after receiving blood screened negative for HIV antibody. Thirteen additional adults developed AIDS after receiving tissues, organs, or sperm from HIV-infected donors; four of these adults received tissue, organs, or sperm from a donor who tested negative for HIV antibodies at the time of donation.

## ***HIV Prevalence***

In 1999, CDC estimated that 800,000 to 900,000 persons were living with HIV infection (including those persons with AIDS) in the United States in 1998. Among these persons, approximately two-thirds (575,000-675,000) have had HIV infection or AIDS diagnosed. Researchers estimated that about 72% of the infected were men or adolescent boys and about 28% were women or adolescent girls. By race/ethnicity, an estimated 46% of infected men were non-Hispanic black and 7% were Hispanic; 68% of infected women were non-Hispanic black. Approximately 45% of the infected persons were men who have sex with men and about 16% were injection drug users. The prevalence of HIV infection increased from 1984 through 1992, with a greater relative increase among women.

**Civilian Applicants for Military Service:** Prevalence of HIV-1 antibody in the 5.4 million civilian applicants for military service tested from October 1985 to September 1997 was less than 1% for all racial/ethnic groups. The overall seropositivity rate for males was 0.09%; only African Americans (0.30%) and Latinos (0.12%) exceeded the overall rate among males. The overall sero-positivity rate for females was about half that of the male applicants (0.05%), and only African American females had a higher rate of seropositivity (0.13%).

**Job Corps Applicants:** Job Corps program is a national job training program for economically and educationally disadvantaged young people between the ages of 16 and 24. Persons who are incarcerated, inject drugs, or engage in other illegal activities are excluded; on the other hand, sexual orientation or past drug use does not disqualify applicants. While not representative of all youth, these data provide a snapshot of the continuing toll of HIV infection among the many young people in the United States who are economically and educationally disadvantaged. Analysis of data from approximately 350,000 HIV tests among Job Corps applicants ages 16-21 between 1990 and 1996 indicates that more than 2 per 1,000 of these young people were infected with HIV, with rates among young African American females exceeding 5 per 1,000. African American females had the highest HIV infection rate of any group, 7 times higher than for white females and 8 times higher than for Latinas. Overall HIV prevalence for young women in the study was 50% higher than for young men (3 per 1,000 women compared with 2 per 1,000 men) as a result of higher rates of infection among females between 16 and 18 years of age. Among the older study participants, the differences in prevalence diminished, and at 19, 20, and 21, there were no significant differences in prevalence rates between women and men.

### **Incarcerated Populations**

Disease surveillance often is lacking in correctional settings, but data from 1997 indicate that between 26,000-36,000 inmates were living with HIV, more than 5-7 times the prevalence in the general population, and many experts consider this to be an underestimation. Based on studies from the Bureau of Justice Statistics, CDC/National Institute of Justice, and the National Commission on Correctional Health Care, it is estimated that about 2.1% of all HIV-positive people in the United States are in federal or state prisons. Data show that incarcerated women are more likely to be HIV infected than incarcerated men (3.4% versus 2.2%), and the proportion of incarcerated women who are HIV positive is increasing at a faster rate than the proportion of incarcerated HIV-positive men (11.1% versus 3.8% increases for women and men, respectively, between 1991 and 1997). Latinas and African American women are more likely to be HIV positive than white women (4.2%, 3.9%, and 2.3%, respectively). In the Eastern United States, up to 12.7% of incarcerated women are estimated to be HIV positive, compared with 6% of incarcerated men.

### ***AIDS Prevalence***

#### **Total AIDS Cases**

African Americans and Latinos are accounting for increasingly larger proportions of persons reported with AIDS each year. Not only are more persons of color becoming infected with HIV and developing the AIDS, but they also account for a larger proportion of AIDS cases compared to their representation in the general U.S. population. In 1999, for example, whites made up 71% of the total U.S. population, but only 32% of the adult AIDS cases and 17% of the pediatric cases. In contrast, African Americans represented about 12% of the U.S. population but 47% of adult AIDS cases and 59% of pediatric cases. Latinas, representing about 13% of the U.S. population, made up almost 20% of adult AIDS cases and 23% of pediatric cases. American Indians/Alaska Natives and Asians/Pacific Islanders represent smaller proportions of the total AIDS cases than their representation in the total U.S. population; these two groups, however, may be disproportionately affected in some states.

### **Pediatric AIDS (Children Under Age 13)**

Through December 1999, a total of 8,718 children have been reported with AIDS; 59% are non-Latino African Americans, 23% are Latinos, 17% are non-Latino whites, 0.5% are Asians/Pacific Islanders, and 0.3% are American Indians/Alaska Natives. Among all the children with AIDS, 7,943 (91% ) acquired HIV perinatally (from their mothers); 39% of the mothers of these children were injecting drug users, 18% had sex with an injecting drug user, and 17% had sexual contact with persons with other risk factors for HIV/AIDS. Another 379 (4%) of the children with AIDS acquired HIV through receipt of contaminated blood transfusions, blood components, or tissue; 235 (3%) of the children had hemophilia or a coagulation disorder.

From 1994 through 1998, the annual number of reported AIDS cases decreased by 54%, from 811 cases to 228.

In the last 2 years (between 1997 and 1998), the number of reported pediatric AIDS cases decreased 42%; the decrease was less among Latinos (24%) than among non-Latino whites (36%) and African Americans (32%).

### **AIDS in Older Adults (Age 50 and Above)**

Early in the HIV epidemic, older persons became infected with HIV primarily through receipt of contaminated blood or blood products. Through 1989, receipt of contaminated blood or blood products accounted for 28% of AIDS cases among persons age 60 to 69 and 64% of the cases in persons age 70 and older. In contrast, contaminated blood/blood products were responsible for HIV infection in only 1% of persons with AIDS ages 13 to 49 and 6% of persons with AIDS ages 50 to 59. Currently, persons age 50 and older identified with HIV have a shorter observed AIDS-free interval and a shorter survival period than younger HIV-infected patients, often dying within a month of AIDS diagnosis. This may be due to a delay in HIV testing following the onset of HIV-related illness because they or their health care provider does not perceive older people to be at risk for HIV infection. HIV testing also may be delayed because the AIDS-related opportunistic illnesses that occur commonly among persons age 50 and older can appear similar to other diseases associated with aging. Such conditions include HIV-related encephalopathy and wasting syndrome that may mimic Alzheimer's disease, depression, and malignancies. In addition, AIDS surveillance data indicate that a high proportion of persons age 50 and older with AIDS are reported without an identified risk for HIV infection.

### ***AIDS Mortality***

From the 1980s through 1995, the estimated number of deaths among people reported with AIDS increased steadily. In 1996, however, deaths among persons with AIDS declined for the first time. The death rate decreased 29% in 1996, 48% in 1997, and about 21% in 1998. This decrease was attributed to recent advances in the medical management of HIV/AIDS coupled with the effects of comprehensive, sustained prevention efforts that began in the 1980s. Thirteen percent fewer deaths in 1996 were attributed to HIV/AIDS than occurred in 1995. Between 1993 and 1997, the proportion of non-Latino African Americans among persons who died from AIDS increased from 35% to 51% while the proportion of non-

Latino whites decreased from 48% to 33%. The proportion of Latinos and other racial/ethnic groups, including Asian/Pacific Islanders and American Indians/Alaska Natives were relatively stable at 13% to 14% and 1% respectively.

As of December 1999, a total of 430,441 adults and adolescents and 5,084 children (under the age of 13) had died with AIDS. Among all persons ever diagnosed with AIDS, 59% of adults and 58% of children have died. The annual number of deaths among persons with AIDS has decreased, although AIDS remains one of the leading causes of death among persons 25-44 years of age. The decrease in deaths partly reflects the leveling of the incidence of AIDS-opportunistic illnesses and improved survival among persons with AIDS due to improvements in medical care and the effect of antiretroviral therapies. Almost half of the persons who died with AIDS were non-Hispanic whites, 35% were non-Hispanic African Americans, 17% were Hispanics, and about 1% were American Indian/Alaska Natives and Asian/Pacific Islanders.

In each of the racial/ethnic groups, 41% among persons who died with AIDS were between the ages of 35 and 44. AIDS is now the second leading cause of death for persons between the ages of 25 and 44. While about 33% of the AIDS deaths occurred in persons under age 35, a greater proportion of American Indian/Alaska Natives (43%) and a smaller proportion of Asian/Pacific Islanders (29%) died in this age group. A small proportion of AIDS deaths occurred in persons under age 15: 2% of the non-Latino African Americans, 2% of the American Indian/Alaska Natives, 1.6% of the Latinos, 1.2% of the Asian/Pacific Islanders, and 0.5% of the non-Latino whites.

The main determinants of survival among persons with AIDS appear to be the type and treatment sensitivity of the particular opportunistic infections they acquire, quality of medical care, therapy with antiretroviral agents, increasing use of prophylactic drugs to prevent secondary opportunistic infections, and greater availability of protease inhibitors.

# **Epidemiology of HIV and AIDS Among African Americans**

## ***Introduction***

While it is commonly and accurately stated that African Americans are “disproportionately represented” in the HIV/AIDS epidemic, this term does little to convey the magnitude and specific impacts of the epidemic within this community. On every epidemiologic measure in common use, when compared to the four other federally recognized racial/ethnic groups (White, Asian/Pacific Islander, Native American/Alaskan Native, Latino), African Americans have the highest rates of prevalent HIV infection, the highest HIV and AIDS incidence, the highest HIV/AIDS mortality rates, and the highest years of productive life lost.

Studies suggest that African Americans are more likely than members of other racial/ethnic groups to have multiple adults within a family infected with HIV. Further, those already infected are less likely to use the newest and most effective antiretroviral treatment regimens.

## ***HIV Prevalence/Incidence Among African Americans***

The National Institutes of Health (Rosenberg) estimated, based on modeling of AIDS surveillance data, that as of January 1, 1993, 2.29% of African American men, aged 18-59, and 0.74% of African American women in that same age group were HIV-infected. This amounts to an estimated 184,000 African American men and 67,000 African American women living with HIV infection on that date.

Another study (McQuillan, et al.) used anonymous data and samples from the third National Health and Nutrition Examination Survey (NHANES III) to estimate HIV prevalence. Of 15,799 persons 18-59 years of age who were interviewed from 1988-1994 (including 5,045 African Americans), 11,203 persons had anonymous HIV test results. This analysis is generalizable to the national civilian noninstitutionalized population, but because of the populations not included (prisoners, homeless, hospitalized patients), HIV prevalence probably is underestimated. The weighted prevalence of HIV infection was 0.32% for all participants and 1.1% for African Americans (95% confidence interval [CI] 1.05-3.00). African American men (1.78%) were three times more likely to be infected than African American women (0.55%). The authors estimate that 189,000 African Americans nationwide were HIV infected, including 137,000 men and 51,000 women. When adjusted for differential non-response, it was estimated that 206,000 African American men were infected (as opposed to the unadjusted estimate of 137,000).

In nearly every population included in various national HIV seroprevalence surveys, African Americans showed high rates of HIV infection (i.e., significantly higher than other racial/ethnic groups). For example, among STD clinic patients studied in 1992-1993, African American men who reported having had sex with men had a much higher HIV seroprevalence (median 43.6%) than white men who reported having had sex with men (median 23.2%).

Because of the long and variable time between HIV infection and AIDS, surveillance of HIV infection provides a much clearer picture of the impact of the epidemic, especially in young people, than surveillance of AIDS cases. CDC analyzed data from 25 states that had integrated HIV and AIDS reporting systems for the period between January 1994 and June 1997. In these states, young people (aged 13 to 24) accounted for a much greater proportion of HIV than AIDS cases (14% versus 3%). Nearly half (44%) of the HIV infections in that age group were reported among young females, and well over half (63%) were among African Americans. The study also showed that even though AIDS incidence (the number of new cases diagnosed during a given time period, usually a year) is declining, *there has not been a comparable*

*decline in the number of newly diagnosed HIV cases among young people.*

In states that confidentially reported HIV infections in 1999, a total of 64,299 HIV infections (not AIDS) were reported among African American men, women, and children. This number represents 52% of all HIV infections reported in 1999 in these states. In 1999, African Americans represented 46% of all men reported with HIV infection (not AIDS), 68% of all women, and 64% of all children under the age of 13 in these states.

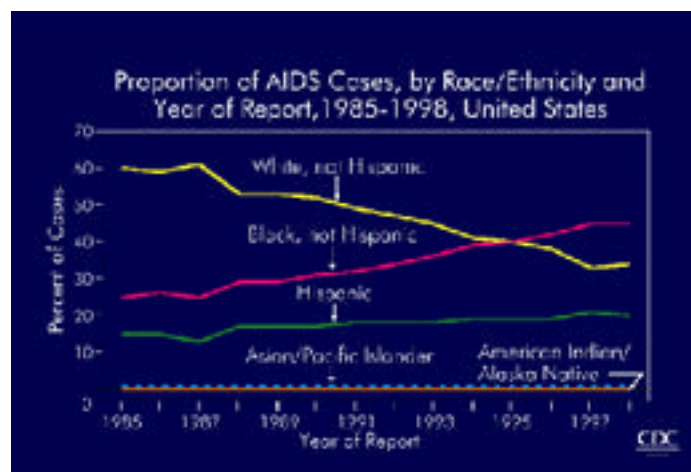
Among African American adolescents between the ages of 13 and 19, more cases of HIV infection are reported among young women than young men. Through December 1999, in the states that have implemented confidential HIV reporting, 1,965 cases of HIV infection have been diagnosed among young African American women and 1,242 cases among young African American men in that age group. Biological factors may influence the higher risk for HIV infection in young women, as well as sexual behaviors such as having sex with older male partners (who are more likely to be infected than their peers).

While the risk of HIV transmission for African Americans is most strongly explained by behavioral factors, recent studies have suggested that biological factors that may facilitate or impede transmission are not identically distributed across racial/ethnic groups. These factors are associated with differential susceptibility to HIV acquisition and with frequencies that differ between African Americans and whites (McNicholl 1997).

Also, the likelihood of exposure to HIV is higher for persons who live in areas of high HIV prevalence, which is the case in many communities of color.

### ***AIDS Prevalence/Incidence Among African Americans***

In 1998, for the first time, the number and proportion of annual AIDS cases reported among African Americans (117,890; 40%) exceeded that among whites (114,846; 39%). This “parity” is occurring despite the fact that African Americans make up 12% of the U.S. population and whites constitute 72%.



When race-specific population sizes are used to calculate population-specific AIDS rates (per 100,000 persons), the 1999 annual incidence rate among African American adults and adolescents reported with AIDS (84.2) is more than 8 times that among whites (9.0). The 1997 AIDS incidence rate for African Americans decreased by 7%, but this decrease was not as great as that observed among whites (23%).

Among African Americans (as among whites), this epidemic is more severe among men than among women. The 1999 AIDS incidence rate (125) among African American men is nearly eight times the rate (16) for white men. Among African American women, the rate (49) is more than 24 times higher than the rate (2) for white women. Between 1996 and 1998 (the most recent year such analyses were conducted), new AIDS diagnoses among African American gay and bisexual men increased dramatically in several urban areas: 10.2% in New York City, 5.7% in Los Angeles, and 4.8% in Atlanta, GA. Over the same time period, AIDS incidence among white gay and bisexual men decreased in all three cities.

Among African Americans reported with AIDS annually from 1993-1997, the proportion whose risk of exposure to HIV was male-to-male sex has steadily declined from nearly a third of cases to less than a quarter (21%) of cases. Similarly, the proportion attributable to injection drug use has fallen over this period, but still constitutes nearly a third (30%) of reported AIDS cases. Cases attributed to heterosexual exposure and those with no identified risk (NIR) at the time the AIDS case is reported have steadily increased and in 1997 accounted for 44% of the AIDS cases among African Americans reported that year. A 6-state follow-up study of persons reported with AIDS in 1992 and initially classified as NIR found that, among the 44% for which risk could be identified, and in all racial/ethnic groups, approximately one-third were MSM (34.4%), a little more than one-third were IDU (37.2%), and nearly one-quarter were infected through heterosexual contact (23.9%). (Klevens 1996)

### ***HIV/AIDS-related Morbidity in African Americans***

Some AIDS-defining conditions have been shown to differ in frequency by race/ethnicity (Chan, 1995). African Americans were less likely than whites to experience CMV disease (13.6% vs 30.5%), cryptosporidiosis (1.2% vs 5.5%), and Kaposi's sarcoma (8.1% vs 25.9%) prior to death, but were more likely to experience tuberculosis (13.0% vs 4.3%). In multisite studies of cancer risk among HIV-infected persons (Biggars 1996, Johnson 1997), the incidence of both Kaposi's sarcoma and non-Hodgkin's lymphoma were lower among African Americans than non-African Americans.

There are suggestions by some clinical investigators that some non-AIDS defining but HIV-associated illnesses are more commonly occurring among African Americans than in other populations. Winston, et al., estimated that, by the end of the decade, HIV-associated nephropathy will be the third leading cause of end-stage renal disease in African Americans between the ages of 20 and 64. They suggest that underdiagnosis and lack of surveillance information are leading to limited recognition of the impact of this condition on the health of African Americans. Similarly Torok, et al., identified increasing mortality from thrombotic thrombocytopenic purpura (TTP), in part associated with the developing HIV epidemic. Mortality rates for African Americans with TTP are 3.4 times that for whites. However, an analysis of the multi-state Adult and Adolescent Spectrum of Disease Project found that African Americans with AIDS had a lower incidence of thrombocytopenia (of all types) than did whites (Sullivan, 1997).

Other researchers (Hu, et al.) examined the differences in AIDS-defining illnesses by race/ethnicity and, when controlling for other demographic and exposure risk categories, found reduced magnitude of prevalent differences. They suggest that much of the remaining observed differences may be influenced by underlying differences in etiologic exposures, diagnosis, and access to care between racial/ethnic groups (Hu 1995). However, no published study has yet directly examined this hypothesis.

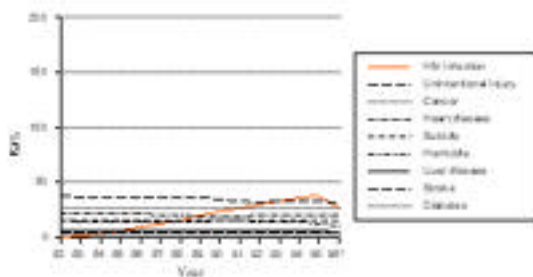
### ***HIV/AIDS Mortality in African Americans***



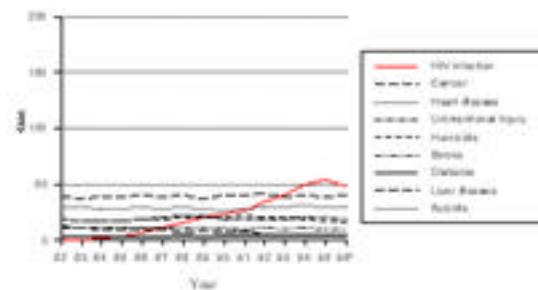
HIV infection was the leading cause of death among persons 25-44 years in 1994 and 1995. In 1995, HIV caused almost 31,000 deaths, or 19% of the total in this age group. The death rate fell to fifth place in 1997 and 1998, causing approximately 8,500 (7%) of the total in this age group in 1998. Among African American men 25-44 years old, HIV infection has been the leading cause of death since 1991, when it surpassed homicide in the ranking of causes of death. HIV infection caused almost 9,000 deaths (32%) of all deaths in this age group at its peak in 1995, but only about 3,000 deaths (16%) of the total in 1998. Among African American women 25-44 years old, HIV infection was the leading cause of death from 1993-1996, and then fell to third place, after cancer and heart disease in 1998. HIV infection caused more than 3,000 deaths (22%) of all deaths in this group in 1995 and about 1,500 deaths (13%) of the total in 1998. Between 1987 and 1997, the proportion of African Americans who died from HIV increased from 30% to 52%, while the proportion of whites decreased from 69% to 47%.

### Rates and Cause of death by race and gender, 1982-1996

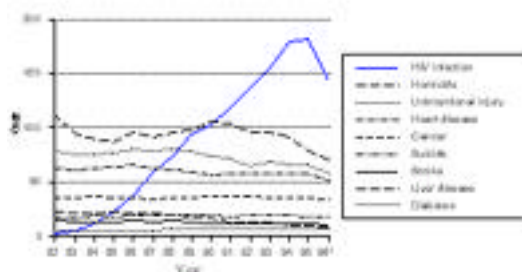
**Death Rates in Persons Aged 25-44  
All Races, Both Genders**



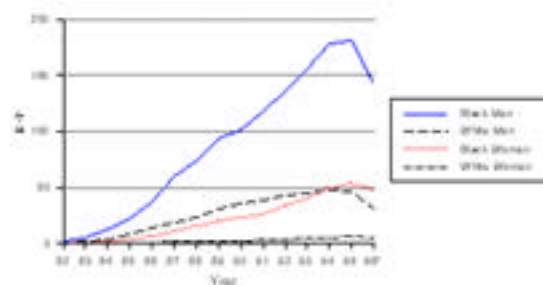
**Death Rates Among Black Women Aged 25-44 Years**



**Death Rates Among Black Men Aged 25-44 years**



**Death Rate from HIV  
Among Persons Aged 25-44 Years, By Sex and Race**



Because HIV infection affects mainly young and middle-aged adults, its impact should be measured not only in terms of numbers of deaths, but also the extent to which those deaths are premature, which can be expressed as the potential years of life lost before reaching old age. In 1995, the most recent year for which the analysis is complete, HIV became the leading cause of years of potential life lost before age 75 years (YPLL75) among African American men, accounting for 15% of the years lost due to all causes. HIV was the fourth leading cause of YPLL75 among African American women, accounting for 9% of the years lost due to all causes. (Health United States 1996-97, NCHS).

Similarly, Lai reports that for the total U.S. population of working age (15-64 years), the elimination of HIV/AIDS deaths may result in an increased life expectancy (0.20 years) similar to that accomplished by a 50% reduction in heart disease (0.20 years) or cancer (0.27 years). However, among African American men of working age, the increased life expectancy (0.82 years) would be virtually the same for the elimination of HIV/AIDS as for the elimination of heart disease (0.90) or cancer (0.76). While there was little change for other gender/race groups from 1987 to 1992, the potential gains in life expectancy for African American men of working age by elimination of HIV/AIDS rose from 0.36 years to 0.82 years (228%).

#### Potential Gains in Life Expectancy (Lai, 1997)

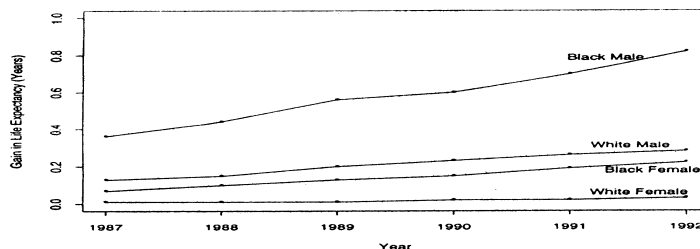


Fig. 1. Potential gains in life expectancy (years) for white men and women, and black men and women of working age of the United States by elimination of deaths from HIV/AIDS (1987-1992).

#### ***Risk Behaviors for HIV/AIDS in the African American Community***

Through December 1999, most African American men reported with AIDS acquired HIV through male-to-male sex (38%) or injection drug use (35%). Eight percent of African American men with AIDS reported both these risk behaviors. Heterosexual contact accounted for 7% of HIV infections among African American men and receipt of blood transfusion, blood components, or tissue for 1%; risk was not reported or identified for 11%.

The greatest risk for African American women since the epidemic began has been injection drug use, accounting for 45% of the total cases in women. Heterosexual contact has accounted for 36% of total cases in African American women. However, for AIDS cases reported in 1999 alone, more women acquired HIV through heterosexual contact (38%) than injection drug use (25%), though sex with an injection drug user accounted for the greatest number of cases attributed to heterosexual transmission among women.

While many behavioral studies have been done with local or special sub-samples of African Americans, there is little information from population-based studies that is generalizable to the overall African American population. Data reported below are only those from large multi-site or population-based samples.

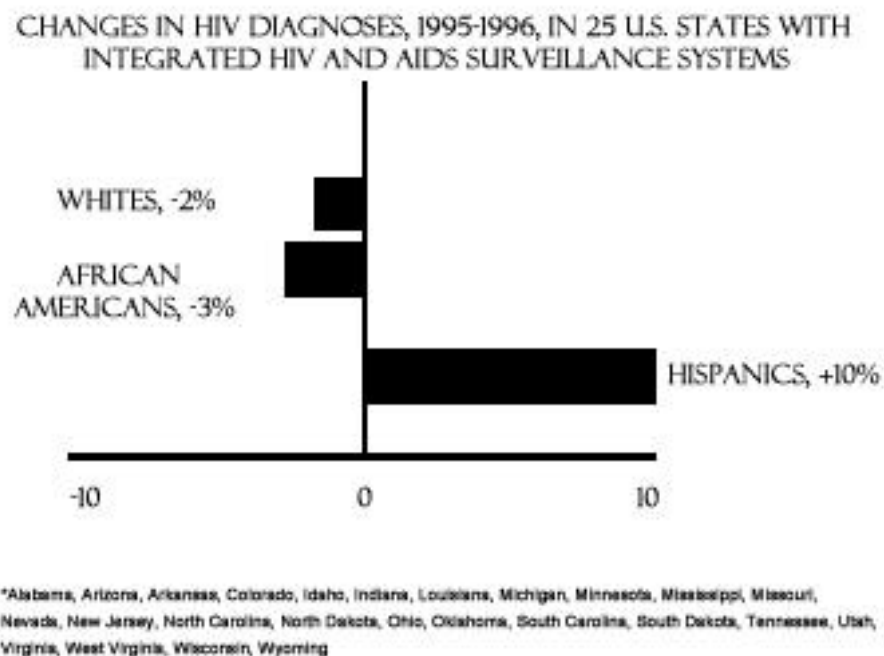
Population-based data on sexual behaviors among street-recruited injection drug users in 19 cities were reported by Friedman in 1993. African American men and women reported unprotected vaginal sex in the prior 6 months at the same rate (22%). African American women reported condom use during a higher proportion of sexual activities (anal, oral, or vaginal) than men (26% vs. 21%). A higher proportion of males (14%) reported any unprotected anal sex in the prior 6 months than females (9%). More than half the African American male (51%) and female (57%) injection drug users reported high rates of sex with a non-IDU partner.

Using a national household survey, the Substance Abuse and Mental Health Services Administration (SAMHSA) estimates that, in 1996, 0.8% of African Americans (189,000) had ever injected drugs (cocaine, heroin, or amphetamines) and 0.1% (22,000) had injected in the previous year. Among the African American respondents, 7.5% reported using any illicit drug in the prior month (including marijuana, cocaine, inhalants, hallucinogens, heroin, or non-medical use of prescription psychotherapeutic drugs): 3.8% of those 35 years or older, 10.6% of those 26-34 years, 15.7% of those 18-25, and 8.6% of those 12-17 years old. These estimates are considerably lower than those reported from the same survey in 1991 suggesting that HIV exposure through injection drug use may be falling for African Americans.

# Epidemiology of HIV/AIDS Among Latinos

## *Introduction*

Latinos in the United States include a diverse mixture of ethnic groups and cultures. With more than 25 million Latinos, the United States has the fifth largest Latino population in the world, following Mexico, Spain, Argentina, and Colombia. Although Latinos represent an estimated 13% of the total U.S. population, they account for 20% of the 733,374 total AIDS cases reported in the United States through December 1999. Most HIV and AIDS cases reported to date among Latinos have been among men, although the proportion of cases among women is rising.



## *HIV Prevalence/Incidence Among Latinos*

A CDC study examined data from January 1994 through June 1997 from the 25 states that had integrated HIV and AIDS surveillance. This study showed that HIV diagnoses increased 10% among Latinos between 1995 and 1996 (the most recent year for which overall trends can be examined). However, the number of cases reported among African Americans was relatively small. At the same time, HIV diagnoses declined slightly among African Americans (-3%) and among whites (-2%) in these states. Of the 7,200 young people ages 13-24 years who were diagnosed with HIV from January 1994 to June 1997, 5% were Latino.

Many states with large Latino populations have not yet implemented HIV reporting; however, the state that reported the most HIV infections in 1997, Florida, does have a large Latino population. (Florida began HIV

reporting in July 1997 and reported 1,948 infections from July to December of that year.) In all the states that confidentially reported HIV infections in 1999\*, a total of 9,296 HIV infections (not AIDS) were reported among Latino men, women, and children. This number represents nearly 8% of all HIV infections reported in 1999 (122,607) in these states. In 1999, Latino Americans represented 8% of all men, 7% of all women, and nearly 10% of all children under the age of 13 reported with HIV infection (not AIDS) in these states.

Cases of HIV infection reported with no identified risk and those associated with heterosexual transmission made up more than one-half of the total number of cases reported among U.S. Latinos in 1999 (NIR, 23%; heterosexual transmission, 17%). About 39% of HIV cases among U.S. Latinos in 1999 were attributed to male-male sex and 20% of HIV cases were attributed to injection drug use.

\*Alabama, Arizona, Arkansas, Colorado, Florida, Idaho, Indiana, Louisiana, Michigan, Minnesota, Mississippi, Missouri, Nebraska, Nevada, New Jersey, North Carolina, North Dakota, Ohio, Oklahoma, South Carolina, South Dakota, Tennessee, Utah, Virginia, West Virginia, Wisconsin, Wyoming. Connecticut, Oregon, and Texas report pediatric cases only.

## ***AIDS Prevalence/Incidence Among Latinos***

In 1999, 43,681 new AIDS cases were reported to CDC. Of these, 8,967(20%) occurred among Latinos. The AIDS incidence rate (the number of new cases of a disease that occurs during a specific time period) among Latinos was 34.6 per 100,000 population in 1999, almost 4 times the rate for whites (9.0 per 100,000) and almost half the rate of African Americans (84.2 per 100,000 population).

By country of origin, the largest number of U.S. Latinos reported with AIDS in 1999 were born in the United States, followed by Puerto Rico and Mexico.

### **Adult/Adolescent AIDS Cases Among Latinos, by Exposure Category and Place of Birth, Reported in 1999, United States**

Adult/Adolescent exposure category	Place of Birth											
	United States		Central/South America		Cuba		Mexico		Puerto Rico		Totals	
	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%
MSM	910	(31)	282	(42)	78	(39)	546	(50)	321	(14)	2,584	(29)
IDU	806	(28)	24	( 4)	11	( 6)	72	( 7)	1,028	(46)	2,438	(27)
MSM + IDU	120	( 4)	8	( 1)	11	( 6)	30	( 3)			75	( 3)
											271	( 3)
Heterosexual contact	383	(13)	123	(18)	17	( 9)	127	(12)			575	(26)
											1,521	(17)
Hemophilia/coagulation disorder or receipt of blood transfusion, blood components, or tissue	15	( 1)	8	( 1)	—	—	9	( 1)	8	( 0)	52	( 1)
Risk not reported or identified	663	(23)	232	(34)	82	(41)	302	(28)	210	( 9)	2,101	(23)
<b>TOTAL</b>	2,897	(100)	677	(100)	199	(100)	1,086	(100)	2,217	(100)	8,967	(100)

## ***Risk Behaviors for HIV/AIDS in the Latino Community***

Among Latino men, the majority of reported cases have been among gay and bisexual men and injection drug users. Among Latinas, most cases have been the result of heterosexual exposures, although drug use also plays a major role in the spread of infection to women. A large proportion of Latinas were infected through injection drug use or by having sex with an injection drug user.

## ***HIV/AIDS Mortality Among Latinos***

Among Latino men 25-44 years of age, HIV infection was the leading cause of death from 1993-1997, causing 29% of deaths in this group in 1995. Among Latinas, 25-44 years of age, HIV infection was the second leading cause of death from 1993 through 1996. HIV infection caused 20% of deaths in this group in 1995, but only 9% in 1997.

# **Epidemiology of HIV/AIDS Among American Indians and Alaska Natives**

## ***Introduction***

There are 557 federally recognized American Indian and Alaska Native tribes in the United States with vast diversity in heritage, culture, and language. The Indian Health Service, tribally operated health care facilities and Indian urban centers are their primary federal health care providers. In 1997, about 1.43 million American Indians and Alaska Natives, representing about 60% of their total population, were eligible to receive health services from the above health care providers. These persons resided on or near reservations, rural and urban areas where the Indian Health Service, tribally operated health care facilities and Indian urban centers have responsibilities to provide health care and referral services.

## ***HIV/AIDS Among American Indians and Alaska Natives***

In 1999, there was an average of 11.4 American Indians and Alaska Natives per 100,000 population reported with AIDS. American Indians and Alaska Natives comprise the smallest proportion of AIDS cases of any of the reported racial and ethnic groups. As of December 31, 1999, there were 2,132 reported AIDS cases among American Indians and Alaska Natives. There were 1,743 AIDS cases reported among adult males, 358 among adult females, and 30 among children under age 13. These numbers, however, may under-represent the total impact on American Indian and Alaska Native communities. Misreporting the ethnicity of American Indians and Alaska Natives as either white or Latino in various disease surveillance systems, including that for HIV/AIDS, has been documented.

About 69% of the total reported AIDS cases among American Indians and Alaska Natives reported through 1997 were in 10 states: 25% in California, 11% in Oklahoma, 7% in Washington State, 5% in Arizona, 4% in Alaska, and 3% in each of the following states: New Mexico, Texas, Minnesota, North Carolina, and New York. All of the above States are located within Indian Health Service, tribally operated health care facilities and Indian urban centers for health care and referral services.

## ***Risk Factors for HIV/AIDS Among American Indians and Alaska Natives***

Among the AIDS cases reported among American Indian and Alaska Native adults and adolescents, injection drug use was more of a risk factor for women than for men. Only 16% of the AIDS cases among adult and adolescent men could be attributed to either their own injection drug use or sex with an injection drug user, compared with 46% of the AIDS cases among women. More of the male (47%) than female (35%) cases were attributed to sexual contact with someone who was not an injecting drug user. No risk exposure information was submitted with the AIDS case reports for 6% of the men and 14% of the women.

Through December 31, 1999, almost all (90%) pediatric AIDS cases among American Indian and Alaska Native children under the age of 13 were due to perinatal (mother-to-infant) HIV transmission. Forty-eight percent of these cases in children were directly related to injection drug use by one of their parents, and in about 26%, through sex with an injection drug user. Other sexual contact (11%) and unspecified risk (3%) accounted for the remaining cases among the mothers.

## ***HIV/AIDS Mortality Among American Indians and Alaska Natives***

Between 1987 and 1993, HIV-related death rates per 100,000 population were lower for American Indians and Alaska Natives living in Indian Health Service and tribal health care areas compared with the overall U.S. rate for American Indians and Alaska Natives regardless of where they lived.

### ***Findings from the National Native American AIDS Case Management Network***

In late 1993, the Indian Health Service AIDS drug assistance program was eliminated due to the decision to mainstream the care of patients with HIV/AIDS. This prevented bulk purchasing of expensive drugs and cessation of the Indian Health Service monitoring system. In response, the National Native American AIDS Case Management Network (NNAAPC) was developed. An update on HIV/AIDS among American Indians and Alaska Natives is provided by individual programs such as the NNAAPC. Funded by HRSA, the NNAAPC is a free-standing model of AIDS case management services for HIV-infected American Indians. It is considered to have improved access to a wider range of services, to be relatively inexpensive to operate, and to have increased collaboration and cooperation between various service providers. The program provided traditional healing and culturally-specific programming as well as referral, emergency client assistance, HIV prevention, education, counseling, and social and psychological support.

The NNAAPC clients were infected predominately by sexual exposure; a few were infected through injection drug use. The program developed a standardized intake process to collect data on its clients and presently has 11 sites funded throughout the United States. As of September 1996, the national network was serving 433 clients representing 82 tribes. The clients were mostly male (80%) and included 343 American Indians, 19 Alaska Natives, 62 native Hawaiians, and 4 Central or South American Indians. The clients' ages ranged from 4 months to 60 years, and the mean age at entry was 33.8 years. The average T-cell count at intake was 323 and average interval between the date of diagnosis with HIV infection and date of entry into the program was 3.03 years. Most of the clients rely on public funds (especially Medicaid), and 14.6% of clients have private medical insurance. The majority have multiple problems in addition to their HIV/AIDS status. Most have a history of alcohol problems, almost half have drug abuse problems, more than one-fourth have been homeless at some point in their lives, and about one-fifth have a history of mental illness. More than one-fourth are receiving mental health treatment at entry.

### ***Findings from the New Mexico Health Resources Center of New Mexico***

The New Mexico Health Resources Center conducted a statewide survey of providers to determine the extent of the HIV/AIDS problem in New Mexico. HIV was not made a reportable disease in that state until January 1998. New Mexico has 21 tribes, all differing in their beliefs, attitudes, behaviors, and approaches to dealing with their community's health. The Albuquerque Area Indian Health Service serves 64,242 Native Americans, providing managed care service since the mid-1990s. It provides health care to the Jicarilla and Mescalero Apaches and the Navajo communities of Alamo, Canoncito, and Ramah; the Southern Ute Tribes; the Ute Mountain Ute Tribe in southern Colorado, southern Utah; and 20 Pueblos in New Mexico and Texas.

According to the Indian Health Service in 1992, the HIV mortality rates for Indian Health Service areas in New Mexico were lower than that of the total United States for all races: 3.6% for the Albuquerque Area, 1.6% for the Navajo Area, and 2.2% for the Phoenix Area, compared with 12.6% overall in the United States. A survey of Native-specific and HIV-specific service delivery health care and community based



sites in New Mexico was conducted. The majority of cases have been in the urban communities, which consist of members from tribes inside and outside New Mexico. Once a Native American client is near the “end stage” of AIDS, they may move home to be near family for support, to receive care from an Indian Health Service facility if nearby, or to receive alternative therapies from their traditional healers. Because some Native Americans believe that AIDS is a “white man’s disease,” Native Americans may be disowned by their mothers or entire family, may move to urban area, or may leave the state.

Male-to-male sex (MSM) was the leading cause of HIV transmission in New Mexico among Native Americans, with a significant rate of HIV transmission through injection drug use. As of November 1997, more than half of New Mexico’s AIDS cases were among whites (59.6%) and Hispanics (32.2%); only 4.1% were among blacks, 3.8% among Native Americans, and 0.3% among Asian/Pacific Islanders. In New Mexico, 61 Native American AIDS cases were reported, most from Bernalillo County (25 cases) and the northwestern part of the state (21 cases). Most (85.2%) were male.

Of the Native American males with AIDS, the modes of exposure were as follows: men who have sex with men (57%), men who have sex with men and also inject drugs (17%), injection drug use (16%), heterosexual contact (3%), and hemophilia (2%).

Of the Native American females with AIDS, the modes of exposure were heterosexual contact (35%), injection drug use (46%), and risk not specified (14%).

At diagnosis, 67.2% of the Native Americans were not living on a reservation. From 1993 through 1997, the primary mode of transmission for native Americans remained male-to-male sex, but the proportion of native American cases attributed to injection drug use and heterosexual contact increased.

## **Epidemiology of HIV/AIDS Among Asians/Pacific Islanders**

In 1999, there was an average of 4.3 Asians/Pacific Islanders (A/PI) reported with AIDS for every 100,000 A/PI population. Asians/Pacific Islanders comprise a smaller proportion of AIDS cases than any other racial and ethnic group except American Indians/Alaska Natives. As of December 31, 1999, there were a total of 5,347 AIDS cases reported to CDC among Asians/Pacific Islanders. Reports of AIDS in the A/PI community included cases in 4,670 adult males, 629 adult females, and 48 children under age 13. Among the Asian/Pacific Islander adults, sexual contact accounted for more of the adult AIDS cases among men (73%) than women (49%). Injection drug use was more of a risk factor for women than for men. About 5% of the AIDS cases among adult men and 17% among women were attributed to injection drug use. The risk exposure category was not reported or identified for 11% of the men and 18% of the women.

### ***State/Local Data***

Based on the 1990 census, states with the highest percentage of the Asian/Pacific Islander population are Hawaii (61.8%), California (9.6%), Alaska (3.6%), Illinois (2.5%), Maryland (2.9%), New Jersey (3.5%), New York (3.9%), Nevada (3.2%), Washington (4.3%), Virginia, (2.6%), Oregon (2.4%), and Massachusetts (2.4%). Cities with large Asian/Pacific Islander populations include San Francisco (29.1%), Los Angeles (9.8%), New York City (7.0%), Houston (4.1%), and Chicago (3.7%).

Los Angeles and San Francisco provided the following data on Asians/Pacific Islanders in their comprehensive HIV prevention plans in 1995. The Los Angeles HIV Prevention Community Planning Group reported the average annual AIDS rates for the period between 1985 and 1993 by specific Asian/Pacific Islander ethnicities. The highest average annual AIDS rate per 100,000 population was among the Thais (12 per 100,000) and the Samoans (10 per 100,000). The annual AIDS rate was 6 per 100,000 for the Filipinos, 5 per 100,000 for the Japanese, 4 per 100,000 for the Vietnamese, and 1 per 100,000 for the Chinese and Koreans.

Asians/Pacific Islanders make up the largest ethnic group in San Francisco and comprise 30% of the total San Francisco city and county population with 39 distinct cultural and linguistic groups. As of 1995, San Francisco had an estimated 3% of all Asians/Pacific Islanders in the United States, but 21% of the total Asians/Pacific Islanders with AIDS. Between 1986 and 1988, the percent of Asians/Pacific Islanders with AIDS in the city increased 224%. Between 1992 and 1993, the percent of Asian/Pacific Islander cases increased 30%; this rate of increase was higher than for any other racial/ethnic group in the city. Newly diagnosed AIDS cases between 1990 and 1993 among men who had sex with men (MSM) and those who were MSM who also injected drugs increased 21.9%; this rate of increase was higher than for any other racial/ethnic group in the city.

From 1990 to 1991, the San Francisco Department of Public Health conducted a separate study of HIV/AIDS Knowledge, Attitudes, Beliefs, and Behavior among the Chinese, Japanese, Filipino, and Southeast Asian communities in the city. In the Filipino community study, 80% of the respondents believed AIDS to be one of the most important problems facing the Filipino community, yet 39% believed that Filipinos were less likely than other racial and ethnic groups to contract AIDS. California's comprehensive HIV prevention plan reported that Filipinos living in San Francisco, New York, and Los Angeles had the highest AIDS incidence among all Asians/Pacific Islanders. The perception of low risk among Filipinos may have been due to the fact that more than 75% of cases in their community occurred among men who had sex with men, a group that did not generally reside in neighborhoods with high densities of Filipinos.

## *Implementing a Comprehensive and Effective Community Response to HIV/AIDS in Communities of Color*

### **UNDERLYING CAUSES OF HEALTH DISPARITIES**

Racial and ethnic minority communities are among the fastest growing of all U.S. communities, yet African Americans, Latinos, American Indians and Alaska Natives, and Asians and Pacific Islanders in many respects have poorer health than other communities and remain chronically underserved by the health care system. The concept of health disparities was highlighted in the Department of Health and Human Service's 1985 *Task Force Report on Black and Minority Health*, which detailed the widening disparities between minorities and nonminorities in six health areas: cancer, cirrhosis, diabetes, homicide, unintentional injuries, and infant mortality. HIV/AIDS was added to this list of disparities in 1987 based on the disproportionate impact that the disease was having on racial and ethnic populations. Since then, the disparity in cases of HIV/AIDS in racial/ethnic minority populations has continued to widen. This section of this report outlines the underlying causes of these disparities.

Racial and ethnic disparities related to HIV/AIDS may be due to a variety of influences that must be further researched and documented before effective prevention, intervention, and treatment services can be planned and implemented. Data are needed on the effects of such factors as socioeconomic status, different cultural heritages, social structures, languages, nutrition, and other aspects of lifestyles and health behaviors. Information also is needed on such issues as immigration status and length of residency to help determine access to health care, etc.

As discussed in the Office of Minority Health's report to Congress, "Foundation for Progress: Strengthening the Infrastructure," for some health indicators, "the health status of low socioeconomic status (SES) groups (in which minorities tend to be over-represented) has worsened. Differences in accessibility, utilization, quality of care, or benefits derived from medical care are factors contributing to inequality; however, an increase in economic inequality between SES groups is the driving force behind the rise in health disparities."

Socioeconomic differences are largely responsible for many disparities in health status along racial/ethnic lines. Adjustment for socioeconomic status substantially reduces but does not eliminate these inequalities in health outcomes. It is also important to note that in some areas where improvement in health status has occurred, the rate of improvement for minorities did not equal the rate of improvement for nonminorities. Thus, while the overall health problem is being addressed, the gap in actual health status is not being closed.

One reason for the persistence of racial differences, despite adjustments for SES indicators, is that the commonly used SES indicators do not fully capture the differences in economic status between households. For example, wealth-related racial differences are much larger than income-related racial differences. Another reason is the failure of most studies to examine the role of racism and health. Racism can transform social status so that SES indicators are not equivalent across races. Racism can restrict access to public education, health care, housing, recreational facilities, and a host of other services.

While the impact of HIV/AIDS and other diseases in racial/ethnic minority communities may be explained somewhat by socioeconomic status, the little research that exists has indicated that race and ethnicity are important correlates in themselves. For example, Kaufman and his colleagues analyzed data from the longitudinal component of the National Health Interview Survey to examine the relationship between income

and mortality in U.S. African Americans and whites. These researchers found that African Americans not only had higher mortality rates than whites at most income levels, but that they derive less protection from higher income.

Race/ethnicity is also an important independent correlate of access to medical care. For example, researchers found that HIV-positive African Americans were less likely than whites to be given antiretroviral drugs, including medication to prevent pneumonia. Only 58% of the eligible African American patients compared with 82% of eligible white patients received drug therapy. These researchers studied 838 patients for 2 years: age, sex, mode of HIV transmission, type of insurance, income, education, or place of residence did not relate to the differences in therapeutic regimen. The only documented difference was race. Minorities and IDU were less likely to receive ZDV and pentamidine, even after controlling for ability to pay.

Beyond these factors, some societal efforts to help communities, while meaning well, may not always be appropriate. For example, in some racial and ethnic groups, there is a tension between society's value on individual empowerment and the group's tradition which values the cohesion and allegiance to the group. In other cases, the issue is not whether people at risk know or care about avoiding HIV infection, the disparity is between what people know they need to do to avoid HIV infection and what resources are available to make those choices.

Because HIV/AIDS among minorities is compounded by a variety of other factors, including poverty, unemployment, educational disadvantages, alcohol and substance abuse, and other health problems (especially tuberculosis), combating the problems of HIV/AIDS in communities of color will require more than health resources. Housing, employment, and especially education are as important as medical treatment, sanitation, and good nutrition. For example, one study examined the relationship of education to death from HIV-related conditions in persons with AIDS who were ages 25 to 64. Males with high school education or less were almost twice as likely to die of HIV-related conditions than males with more education. Females with high school education or less were about 6 times more likely to die of HIV-related conditions than females with more education.

In general, there are numerous factors that have contributed to the continued disparities in health status between minorities and whites. These are not unique to AIDS, but must be addressed if HIV prevention efforts are to be successful, if needed care and treatment will be accessible and utilized, and if research will be conducted. The factors include:

- abaccess-to-care issues, including cost, culture, language, infrastructure, data;
- abdenial within the community that HIV/AIDS is a problem; and
- abgovernmental inaction in terms of priority-setting, funding, and technical assistance.

### ***Access to Care***

Access to health care is the major determining factor of health outcomes. Persons who do not have health insurance or do not access health care on a regular basis because of financial considerations, transportation issues, cultural issues, etc., have health outcomes that are dramatically different from those who do.

Numerous studies have shown that minorities are less likely to have health care coverage than whites, mainly because of the cost of insurance and the lack of insurance coverage offered through the workplace. Low-

income families often spend greater proportions of their income on health care services than whites. Lack and cost of coverage often translates into no services, other than in emergency rooms or during later stages of an illness.

In addition, members of minority communities who do have health care coverage use the health care system less often than non-minorities with health care coverage. Studies indicate that up to one-half of blacks and Hispanics did not visit a physician in the past year, compared to only one-third of whites.

Cultural issues also play a role in an individual's decision to seek health care services. In many cultures, especially in minority populations, people go to the doctor only when they are very sick, if even then. Many individuals rely on family members for care and comfort and often see death as a natural part of life. This often means that individuals may not seek health care, since illness is an inevitable part of life. If they do seek medical care, cultural norms often result in their not asking questions or minimizing their symptoms so as not to "burden" the doctor. They may respond to a question with a "yes" so they do not appear to contradict an authority figure. It is important to note that culture is not simply determined by ethnicity or a particular set of beliefs, norms, and values. Rather, it also involves history, economics, and social and political status. It is affected by the individual's level of acculturation and by the level and types of interaction an individual has with the dominant culture.

A key component of culture is language, and language is a key determinant of access to care. Given the severe under-representation of racial and ethnic minorities in the health professions, minority patients often are treated by a doctor who may not understand the patient's culture or language. A person who speaks limited English may not be able to navigate the complex health care delivery system in the United States; they may decide not to seek preventative services and rely instead on the emergency room. Even if they do access medical care, they may find it difficult to understand the medical questions being asked or the instructions for taking medication or for treatment follow-up. The scarcity of health care professionals serving minority populations who can understand the language or culture of that population contributes to a gap in services that, if not bridged, can compromise a patient's care. Clearly a patient will not be likely to return for follow-up or participate in the diagnosis if he or she is offended when the health care provider asks personal, although medically necessary, questions or engages in what the patient considers inappropriate. All too frequently, janitors, secretaries, relatives, or other medically untrained individuals are asked to provide translation or interpretation services. This is inappropriate and violates the level of trust and respect that is necessary between a health care provider and a patient.

The infrastructure of the health care delivery system also affects the ability of minority individuals to access care. Given the historic lack of funding for health programs in general in minority communities, the networks necessary to ensure comprehensive, linguistically and culturally appropriate HIV prevention, care, and treatment services have not been established. The AIDS epidemic has added an additional and costly burden on the already overburdened facilities, many of which were struggling to make ends meet before the AIDS crisis. Minority communities continue to play "catch-up" in terms of obtaining funding for programs and organizational development.

Patients may be referred to nonminority providers, but this means that patients may have to deal with a medical staff that has little experience working with minority clients or does not want to work with minority clients. Such facilities often are located in areas of town that are not convenient to minority patients, requiring them to travel long distances for each visit. Since each visit may cause the loss of a day's wages, patients must make choices based on what is more important, a visit to the doctor or money to pay for rent

or food for the children. Other concerns include limited hours of clinic operation and waiting times for an appointment, both in terms of scheduling the appointment and waiting in the office. Many minority patients do not have “sick leave,” and too many trips to the doctor can result in the loss of employment. Facilities must be open early to accommodate those who need to go before work, open late to accommodate those who can only go after work (for many this means after their second job), and on weekends, including Sundays, to accommodate those who work 6- or 7-day work weeks.

For many individuals with multiple health problems or difficult family situations, the range of services available at a particular location could determine whether or not they will access medical and other services. If a person has to go one place for family planning, another for prescription drugs, and yet another for blood draws, their ability or willingness to navigate and participate in the system may be diminished.

A compounding factor related to infrastructure is the lack of data on which to establish baselines and sub-objectives for determining if health improvement targets have been met. The inability to measure improvement may influence whether or not funders continue to provide support. Many funders, including the federal government, rely on evidence of proven need to determine whether a program will be funded. Organizations that lack sufficient data specific to HIV/AIDS in racial/ethnic populations may not be able to convince funders that it is a health problem that must be addressed in these communities. Further, the lack of accurate data on HIV/AIDS in minority populations may cause policy makers to make inappropriate decisions, resulting in an increased burden of disease and death in these communities.

Racial and ethnic populations remain in a “Catch-22” situation when it comes to data, especially at the state and local levels, where information is most urgently needed for targeting resources. For much of the early to middle stages of the HIV/AIDS epidemic, only limited race-specific data (White/African American) were collected and reported. Without data, it was impossible for other racial/ethnic populations (Latinos, Asian/Pacific Islanders, American Indians/Alaska Natives) to document need within their communities. Since these populations could not fully document need, they were unable to obtain funding for programs, including data collection. The reliance of policy makers and funders on hard data, as opposed to anecdotal information, resulted in the lack of needed attention to the health problems of racial and ethnic populations. Until fairly recently, many states would not collect, report, analyze, or share data for Latinos and their subpopulations, and few states, even today, report data for any Asian subpopulations. Data on Native Americans are rarely, if ever, reported by tribe. Data on African Americans are rarely, if ever, reported by country of birth or origin. The lack of data means that funders and organizations are forced to develop programs that are not targeted to unique audiences. For example, programs are designed for Latinos, but not for Mexican Americans, Puerto Ricans, or Salvadoreans. More importantly, materials are not being developed for specific at-risk groups within these populations (e.g., Korean MSM, Dominican IDU). Programs that were developed had to conform to the criteria of the funder. Since programs did not have the data showing that targeting was necessary, funding did not follow.

Because all minorities were considered to be alike, programs targeting multiple minorities were funded rather than programs that targeted a subset of a specific population (e.g., African American MSM or Puerto Rican IDU). It also prevented epidemiologists and, more importantly, the community from truly understanding HIV’s impact within a particular race/ethnicity or culture. Since statistics were not being collected on subpopulations, researchers could not determine that HIV was being transmitted differently within subgroups.

## ***HIV/AIDS: Not a Priority***

For many individuals with minority racial or ethnic backgrounds, AIDS is just one of the myriad of issues that they must deal with on a daily basis. This complicates the development of a community response to the epidemic. Issues such as poverty, homelessness, substance abuse, unemployment, and institutionalized racism, sexism, or homophobia all contribute to keeping the AIDS epidemic from receiving an appropriate level of attention within minority communities. Despite the statistics, many members of minority groups still view AIDS as a gay white male disease, ignoring the fact that those most affected by HIV are part of their own community. This denial is often based on religious beliefs or cultural norms which dictate that matters related to sexual activity or drug use not be discussed publicly or openly. Denial alters the way AIDS is viewed by minorities and affects the success of local prevention and treatment efforts. It also limits the national response to the epidemic, with many national minority organizations still not including HIV/AIDS in their agendas. AIDS is just one more issue on an already full plate.

The past and present effect of “mistrust of government” at all levels must not be overlooked. This mistrust, based on knowledge of past events (the Tuskegee study of untreated syphilis, forced sterilizations of women in Puerto Rico), experiences (immigration from a country where government is usually associated with civil war and/or repression, immigrant bashing by elected officials), or fear (e.g., of deportation if a person were to access services) meant that many people of color often chose no treatment over bad treatment. Even today, opinion polls continue to show that many members of minority communities believe that AIDS was created by the U.S. government as a way to eliminate racial and ethnic minorities.

## ***Governmental Inaction***

Another factor which contributed to the disproportionate impact of HIV/AIDS on racial and ethnic minority populations was the early inaction on the part of the federal, state, and local governments in providing funds for prevention programs specifically targeted to racial and ethnic communities. This delay in action has led many people of color to question the reason for the lack of funding, often ascribing it to racism or to a view that “the government” has long considered homosexuals, drug users, and racial and ethnic minorities, as “expendable.”

Additionally, many minority individuals are concerned by the lack of HIV/AIDS material in languages they understand best, a factor that could be contributing to poor health outcomes in some minority populations. For example, while most—but not all—Latinos are able to speak Spanish, there are numerous dialects of Spanish. The Spanish word for condom in Puerto Rico is different from that used in Peru. The same is true for the many Asian languages, Native American tribal languages, and even African and Caribbean languages. Using the correct words and colloquial sayings is important for message delivery and understanding. In many instances, material is developed in English and simply translated into another language, thus ignoring the important cultural nuances of language and word choice. Yet funding rarely is adequate to produce materials in more than one language, and materials for subpopulations are almost nonexistent. Materials also should be produced at the appropriate reading level for the target audience, and materials for those who cannot read at all are needed as well.

Another funding issue is the imposition of restrictions on the use of funds. Behavioral research has shown that messages the audience can identify with are the most effective, yet content guidelines for federally

funded prevention materials have long been decried by community groups as restricting their ability to be frank, honest, and open in their communications with specific target audiences, including those hardest hit by the epidemic. For example, material developed very specifically for young gay men using language they understand and identify with could be misconstrued as “directly or indirectly promoting homosexual sexual behavior” and would not be eligible for federal funding.

Legal prohibitions also prevent federal funds from being used to support syringe exchange programs despite extensive scientific evidence that such programs can help prevent the spread of HIV infection without promoting drug use. Given that more than 50% of all new HIV infections are directly or indirectly related to injection drug use, many minority communities view the inaction of the government on this issue as limiting their ability to use an effective prevention intervention in their communities.

### ***Conclusion***

It is clear that the health disparities that exist between racial/ethnic populations in the United States are based on more than just socioeconomic status. While socioeconomic status may affect access to care, it does not necessarily affect the quality of care. Other issues, such as denial of the problem, homophobia, racism, institutional barriers related to culture and language, and governmental inaction, have also placed—and continue to place—formidable obstacles in the path of adequately funding and implementing successful prevention programs, services, and research efforts.



*Implementing a Comprehensive and Effective Community Response  
to HIV/AIDS in Communities of Color*

**COMPONENTS OF AN EFFECTIVE AND COMPREHENSIVE  
COMMUNITY RESPONSE TO HIV/AIDS**

A substantial body of research indicates that the quality of HIV/AIDS related services is highly variable by region of the country, city, and community. Practices in HIV prevention education, HIV counseling and testing, initiation and maintenance of anti-retroviral therapy, support services, data collection and evaluation range from minimal to extensive among different communities and even within communities. Despite considerable data suggesting best practices in many of these areas, few standards of HIV prevention and care have been set. As a result, the quality of HIV services varies according to local economics, politics, and community involvement. Not surprisingly, communities of color, which also tend to be communities with modest economic means, limited political power, and impaired infrastructure for mobilization, have not had the ability to mount an effective response to HIV/AIDS. Moreover, without nationally recognized standards of HIV prevention and care, accountability at the local and national levels is lacking.

***Cross-Cutting Issues***

Strategies to address complex public health problems such as HIV and AIDS should recognize the important role that communities play in preventing the spread of diseases. Community members bring knowledge about the community's culture, social norms, and networks, all of which can be used to better define health problems and to devise solutions to them. The importance of community-based programs for improving health is outlined in *Healthy People 2000*. Community-based programs are increasingly comprehensive in taking a positive approach to health and well-being through planned, coordinated, and ongoing efforts. In the area of HIV/AIDS prevention and treatment, there is strong support for, and appreciation of the benefits of, working in partnership with communities to promote healthy behaviors and to reduce risk factors associated with HIV transmission. For example, the premise underlying community planning as the main vehicle for planning preventive services at the local level is the critical role of the community in HIV prevention. Still, there are many challenges associated with government and community partnerships.

One such challenge is defining what constitutes the community. While the notion of community is a complex and changing one, there are several aspects of community that are shared across a diversity of perspectives. Communities, at some point in their development, emerge out of geographical and social relatedness. Even as communities evolve and people disperse from their original location, original community members who have moved away continue to maintain a sense of emotional connectedness to the place and people that formed the basis of earlier social relationships. Communities are also distinguished by shared interests and experiences. In this regard, communities may be formed around ethnicity, culture, occupation, sense of purpose, and common identity.

For purposes of HIV prevention, a community may be defined in terms of (1) individuals and groups that are affected, or likely to be affected, by the problem of HIV/AIDS, and (2) those who may benefit from actions that are developed to control or ameliorate its effects.

Another challenge of partnering with communities is establishing relationships of trust. The problem of mistrust between government and community is especially striking in communities of color. These communi-

ties have histories that involve discrimination through research and treatment delivery. Examples such as the Tuskegee Syphilis Study in African Americans, infertility research among Puerto Ricans, nuclear weapons testing in the homelands of Pacific Islander Americans, and abuses and denial of treatment for Native American Indians help explain the numerous expressions of mistrust of government-supported efforts to study and treat diseases in these communities. A major feature of past injustices in health research and treatment services has been a lack of recognition for the leadership role that these communities must have in developing and maintaining government-community partnerships. Imbalances in power and inequities in the sharing of control have undermined the government's ability to see communities as powerful agents in determining their health outcomes, thus leading to feelings of resentment, anger, and distrust among those who could potentially benefit from such partnerships.

Community empowerment research and intervention approaches aim to reverse this tendency by promoting the participation of communities in actively generating strategies and solutions to the health problems affecting their members. The goal of community empowerment is to increase community competence in defining problems and identifying resources to solve those problems. Efforts are focused on creating social changes (in organizations, institutions, and social networks), thereby impacting programs, policies, and practices that influence individual behavior and health outcomes.

### **Community Assets**

With the goal of empowering communities for health promotion, John McKnight and his colleagues (1993) focus on identifying, assessing, and building upon existing assets in communities. Community assets can be described as the skills, talents, and resources belonging to and generating from individuals, associations, and institutions. For McKnight and others, the beginning point in partnering with communities to deliver prevention and treatment services is identifying a community's capacity. Communities differ in the degree to which they have the ability to devise, implement, and evaluate prevention and health promotion strategies. A capacity assessment focuses attention on the assets of individuals, associations, and institutions by soliciting information about the resources the community has to build relationships that can be used to define and solve their problems.

An assessment of the capacity of individuals should try to reach as many members of the community as possible to learn more about their skills that can benefit the community, what skills they believe are their best, and whether they have had experience working with community associations.

- An assessment of the capacity of associations should begin by looking in local papers, and talking to key opinion leaders and gatekeepers to find out what associations currently exist in the community. This includes finding out what the associations currently do for the community, for instance, an inventory of specific services offered by community-based organizations. Next, the assessment should try to find out what the associations might potentially do for the community and their interest in and commitment to working with other organizations.
- An assessment of institutional capacity should consider other assets that the institution could contribute rather than the goal of the institution (e.g., improving the health of the community in the case of a hospital). For instance, a college might have a political science department that could lend student and faculty expertise to develop petitions and letters for the purpose of improving the safety of its neighborhood.

- A capacity assessment is distinct from a needs assessment because it focuses on strengths rather than deficiencies. Needs assessments begin with the premise that communities have deficits that need to be remedied through interventions by outsiders. Conversely, capacity assessments start with the assumption that communities have talents and capacities that can be drawn upon to define and solve problems.

### **Basic Issues in Community Participation**

Inclusion is the core issue for building community partnerships in HIV prevention and treatment. Who should be included? How and when are they included? Do the decision-makers include the people who are affected by the consequences of the decisions and how much weight do they carry when decisions are being made? Who will be held responsible for the consequences of decisions?

Inclusion means establishing deliberate and explicit mechanisms for enabling the full participation of those that are affected. Inclusion means “grassroots” involvement to the extent possible, for the people most affected, either directly or indirectly. It means making the effort to include individuals and various local organizations (like block clubs and local school councils) whose organizing methods include door-to-door contact, involvement of people beyond their own membership, provisions for “bottom up” planning and decision-making, and creation of indigenous leadership. Persons at the grassroots level, in this context, are people who do not work for organizations that deliver services or conduct research.

### **Collaboration and Partnership**

Collaboration is a shared decision-making, where all those affected participate in making decisions, and all parties are willing to contribute their resources to benefit the partnership.

Collaboration is not a consultative process where opinions are sought from one group, but decisions are made by another; nor is it negotiation where parties with unequal resources use win-lose strategies to protect their interests. True collaboration entails sharing risks, responsibilities, resources, and rewards and includes shared and balanced investment, responsibility, liability, goals, expectations, and benefits. Collaboration requires partnerships among policymakers, funders, researchers, evaluators, communities, families, and individuals.

The resources for partnership must be adequate to support the activities and infrastructure necessary to build and sustain the relationship. Funders must be sensitive to the actual costs of participation and the ability of communities to share those costs. Some communities, especially highly educated middle and upper class communities, can draw on significant, well-established, diverse resources that can facilitate their involvement in delivering HIV preventive interventions and treatment services or can help them mobilize and take effective action if they believe that they are being harmed. Conversely, in communities where basic resources are lacking, infrastructure is inadequate, information is unavailable or unreliable, and day-to-day survival consumes the limited resources that people have, community members must balance the demands of a health promotion partnership against all the other demands in their lives. Poor communities are the most vulnerable to exploitation by researchers, and thus stand to benefit the most from inclusion as equal partners in the research process. But a community cannot be an equal partner if it is solely dependent on the government for the resources needed to act as a partner. Therefore, resources must be available to the community to build its capacity for effective partnering with government.

## **Trust**

To build trust, communities need to experience direct benefit from their relationships with government and to know that individuals and institutions are held accountable for their actions. These aspects are often complicated by legal and ethical issues such as confidentiality, contractual relationships, and proprietary interests. However complex, they need to be spelled out so that communities are assured that they have full access to health-related information and treatment.

In order to function as true partners in health promotion and disease prevention, communities need education and training on pertinent health issues, research processes, and research options for identifying and resolving particular problems. Individuals want full disclosure of information related to health issues and research in their communities expressed in language that they can understand, and they want sufficient time and opportunity to review and understand complex information. They do not want information to be presented in a manner that implies that it has been selectively edited for a less intelligent (as opposed to a less educated) audience.

Studies have shown that one of the pathways to receiving services is through clergy and other representatives of the faith community. Despite the advances in the treatment of HIV/AIDS illness, often times faith communities are not aware of them. Those communities are often overwhelmed and ill prepared to address HIV/AIDS, mental health, and social support services.

Relevant vehicles are needed to explore improving HIV/AIDS education by strengthening the linkages between the health and faith communities. These vehicles can assist in identifying the appropriate role of the federal and state government in the promotion of HIV/AIDS prevention and services utilization within faith communities.

The importance of collaboration between the mental health and faith communities cannot be over-emphasized. This critical linkage between these two partners in healing can lead to a positive impact in three areas. Specifically, collaborative intervention could lead to (1) an increase in the use of community support programs; (2) an increase in the proportion of people with HIV/AIDS who obtain treatment and prevention services; and (3) an increase in the proportion of persons who seek help in coping with personal and emotional disorder associated with HIV/AIDS.

The faith community has a long, rich and proud history of taking care of its own. Because faith traditions are central to the lives of individuals, it must also be central to how care is provided to those with HIV/AIDS. Ongoing collaborative efforts could assist in overcoming the barriers that too often exist for people seeking health and social support services in the context of the faith community. For communities, some barriers include (1) lack of awareness about advances in the treatment of HIV/AIDS; and (2) a sense of being overwhelmed and ill prepared to address the medical aspects of the mental illness. For affected persons, some barriers are (1) lack of knowledge about existing services; (2) language barriers between the affected persons and the respective clergy; (3) lack of awareness about appropriate treatment programs; and (4) fear that family and friends will judge them harshly, viewing the illness as spiritual weakness or the result of sin.

## **Confidentiality Must Remain Paramount**

Confidentiality is one of the foundations of CDC programs, and it must be a requirement under any program enacted. Breaking trust with individuals and communities is highly detrimental to HIV prevention programs

and can lead to illegal discrimination. It is essential that confidentiality protections be included as a provision of any HIV-related prevention activity.

## ***Program Components***

### **Surveillance**

All 50 states, the District of Columbia, U.S. dependencies and possessions, and independent nations in free association with the United States report AIDS cases to CDC using a uniform surveillance case definition and case report form. These case reports **do not** include names or other identifying information, but do include demographic information (patient's date of birth, sex, and race/ethnicity) and as much information as possible related to their disease status (AIDS-defining conditions, date of diagnosis, HIV exposure risk, vital status, etc.). Although information on mode of HIV exposure is not required to transmit a case report to CDC, collection of risk information is very important.

Although completeness of reporting of diagnosed AIDS cases to state and local health departments varies by geographic region and patient population, studies conducted by state and local health departments indicate that reporting of AIDS cases in most areas of the United States is more than 85% complete. In addition, multiple routes of exposure, opportunistic diseases diagnosed after the initial AIDS case report was submitted to CDC, and vital status may not be determined or reported for all cases. However, among persons reported with AIDS, reporting of deaths is estimated to be more than 90% complete.

Until recently, surveillance of AIDS cases provided a reliable picture of trends in the HIV epidemic. Before highly effective treatments were available, researchers could take into account the time between HIV infection and progression to AIDS and estimate where and how many new infections were occurring based on observed cases of disease. Today, trends in AIDS cases and deaths may provide a valuable measure of groups for whom highly effective treatment is not available or has not succeeded. However, they no longer tell us enough about where and how many new infections are occurring—information critical for addressing the increasing need for prevention and treatment services. To allow the U.S. to target programs and resources most effectively, we must be able to keep pace with where the epidemic is going. This means we need to improve our ability to track early HIV infections, *before* they progress to AIDS.

As of December 1999, only 32 states send data to CDC on all confidentially reported cases of HIV infection. Two additional states report only cases of HIV infection among children under the age of 13, and one state reports cases only for children under the age of 6.

### **National Behavioral Surveillance and Risk Factors Studies**

Behavioral surveillance and determinants research serve as an “early warning system” for the epidemic. They identify changing trends in behavioral risk and provide an in-depth understanding of population characteristics of those at risk. Examples of such research include the ongoing monitoring of risk behaviors among youth through various national surveys, research describing psycho-social and cultural characteristics of at-risk populations, and studies describing risk behaviors and their psycho-social and environmental determinants.

Currently, there are several national studies that provide epidemiologic information on HIV/AIDS risk factors. These include the Youth Risk Behavior Surveillance System, the College Health Risk Behavior Survey, and the Behavioral Risk Factor Surveillance System. The Youth Risk Behavior Surveillance System (YRBS) is a national school based survey that is conducted biennially. The YRBS collects data from a nationally representative sample of high school students on sexual behaviors that contribute to unintended pregnancy, HIV infection, and other sexually transmitted diseases. The Behavioral Risk Factor Surveillance System (BRFSS) is state-based and currently active in all 50 states. All participating states in the BRFSS collect data on HIV knowledge, attitudes and testing. The optional section contains questions on personal sexual behavior which some states may elect not to include in their data collection efforts.

### **National, State and Community Data on HIV/AIDS by Race/Ethnicity**

The CDC and Council of State and Territorial Epidemiologists have developed “Suggested Guidelines for Developing an Epidemiologic Profile for HIV Prevention Community Planning.” These Guidelines note: “Although race and ethnicity are not risk factors for HIV transmission, they are markers for complex underlying social, economic, and cultural factors that affect personal behavior and health.” The Guidelines recommend that the epidemiologic profile in each HIV prevention plan further characterize racial and ethnic groups such as the Asian/Pacific Islander population by origin (e.g., Chinese, Filipino, Japanese, Korean, Pacific Islander, etc.). However, such data are not readily available. Noting the need to collect valid information from smaller populations such as Asian/Pacific Islanders, the Guidelines also advise the collection of both quantitative and qualitative data. Qualitative data collection efforts include focus groups, key informant interviews, service provider surveys, community forums, and public hearings.

### ***Behavioral Research***

Nearly two decades of planning, implementing, and evaluating efforts to stem the HIV epidemic in the United States have clearly shown that preventing HIV infection depends not only upon studying and implementing biomedical interventions to thwart the virus, but even more upon influencing millions of individuals in diverse populations to adopt or maintain safe behaviors. Improving the scientific basis for understanding the virus and influencing behavior change is critical to the planning, implementation, and evaluation of prevention programs.

The HIV epidemic in the United States is not static, but is made up of multiple subepidemics that are constantly evolving and intertwined with other significant social problems, such as poverty, homelessness, and substance abuse. Early in the AIDS epidemic, the primary risk group for AIDS was men who have sex with men. Today, the changing profile of HIV/AIDS high-risk groups to people of color and women and an increase in the importance of injection drug use and heterosexual contact as transmission modes suggest a need for refocusing policy, prevention, and intervention efforts.

HIV policy in the past has emphasized individual risk behaviors and individual responsibility for behavioral change. However, behaviors often occur in combination, and social contexts can provide or limit personal choices. For example, many injecting drug users have a combination of HIV risk exposures including multiple sex partners and unprotected sex as well as sharing syringes and “works.” Migrant farm workers are exposed to a variety of infectious diseases, but have problems accessing health care because of their geographic mobility. Social factors that limit personal choice might include cultural attitudes about discussing sexual and other personal matters, a lack of economic resources for testing and health care, and personal relationships that are not conducive to one partner’s asking for condom use or exchanging HIV risk-related information.

A thorough understanding of cultural factors that may influence risk in each population is essential for planning and implementing effective prevention programs. Armed with this knowledge, institutions are more likely to succeed at changing attitudes, teaching skills, and providing resources to foster behavioral change to reduce HIV transmission.

### ***Prevention Science Research***

In response to the 1996 Report of the NIH AIDS Research Program Evaluation Task Force, NIH asked its Office of AIDS Research (OAR) to develop a coordinated and comprehensive HIV Prevention Science Agenda that includes and combines biomedical, behavioral and social interventions. In response OAR established the HIV Prevention Science Working Group (PSWG), which consists of 15 academic researchers, public health scientists, and community representatives. This group also includes liaison members from the Centers for Disease Control and Prevention (CDC) and the Department of Veterans Affairs (VA). The NIH prevention science agenda, as developed with the advice of the PSWG, is informed by a number of principles. The agenda aims to:

- Be comprehensive and multi-disciplinary (biomedical and behavioral/social science);
- Be driven by epidemiology and the state of scientific knowledge;
- Simultaneously consider population, mode of transmission, and social level targeted;
- Include both basic and intervention research;
- Focus on primary prevention; but also address secondary prevention; and
- Be both domestic and international in its orientation.

Within this framework, ongoing prevention science areas include:

- risk factors and mechanisms of HIV transmission;
- intervention to reduce HIV transmission;
- biological and behavioral factors that influence HIV disease progression; and
- negative psychosocial consequences of HIV infection.

### ***Prevention Programs***

The dynamics of the HIV epidemic are different for each affected population. The differences and disparities that exist within communities of color clearly indicate that as we enter the new millennium, the greatest challenge for HIV prevention efforts is in addressing the disparities that exist within communities of color.

Sustained, comprehensive HIV prevention efforts began in the United States in the 1980s. Those efforts have made a significant impact on the overall stabilization of the epidemic. However, the same level of success has not been achieved among communities of color. Forty thousand new infections occur annually—and available data indicate that most are occurring among people of color. These statistics are disturbing. Still, scientific evidence shows that prevention programs work and remain the best and most cost-effective approach for controlling the HIV/AIDS epidemic and saving lives.

**Essential Elements of Comprehensive HIV Prevention Programs.** Comprehensive HIV prevention programs should be based on several key principles and include a number of essential activities. These are highlighted below.

- **A community planning process** ensures that efforts are directed to communities at greatest risk.
- **Epidemiologic and behavioral surveillance** is necessary to effectively guide prevention efforts.
- **Voluntary HIV counseling, testing, referral, and partner counseling** provide a pathway to needed prevention and treatment services.
- **Health education and risk-reduction activities**, including individual-, group-, and community-level programs, provide the skills and support necessary for reducing risks.
- **Accessible diagnosis and treatment of other sexually transmitted diseases** can decrease the risk of HIV transmission.
- **School-based prevention efforts for youth** provide young people the skills and support they need to keep from initiating risky behaviors and to adopt healthy ones.
- **Public information programs** ensure that knowledge and awareness of how to prevent HIV remain high.
- **Training and quality assurance** provide those implementing programs needed skills.
- **Laboratory support** is needed to keep pace with diagnostic and testing services and related research efforts.
- **HIV prevention capacity-building activities** support organizations in expanding their abilities to implement effective programs.
- **An HIV prevention technical assistance assessment and plan** ensures that programs keep pace with prevention technologies.
- **Evaluation of major program activities, interventions, and services** ensures that prevention efforts are effective.

Several of these essential elements are discussed more fully in the following section:

### **HIV Prevention Community Planning**

The goal of HIV Prevention Community Planning, now in its seventh year, is to improve the effectiveness of HIV prevention programs by strengthening the scientific basis and targeting of prevention interventions. In partnership, representatives of affected populations, epidemiologists, behavioral scientists, HIV/AIDS prevention service providers, health department staff, and others analyze the course of the epidemic in their jurisdiction, determine their priority prevention needs, and identify HIV prevention interventions to meet those needs. Community planning groups are responsible for developing comprehensive HIV prevention plans that are directly responsive to the epidemics in their jurisdictions. The community planning process represents a significant paradigm shift, in that the identification of high-priority prevention needs is shared between the health department administering HIV prevention funds and representatives of the communities for whom the services are intended.



A 1999 review of 61 state and local health department applications for federal prevention funds (which are based on the priorities established by community planning groups) indicated that 49 health departments identified men who have sex with men (MSM) as a priority population; 8 health departments identified MSM/IDU; 47 health departments identified substance abuse/IDUs; 45 identified women; 42 identified youth/young adults; and 38 specifically identified persons of color as priority populations. (Note: racial/ethnic minority populations also are included in the categories of MSM, women, and youth.) Since the implementation of community planning, a shift in the allocation of resources has occurred. For example, the funds allocated to health education and risk-reduction activities increased from 23% of the total 1993 award to 39% of the total 1999 award. The funds that health departments allocated over the last two years to support community-based organizations and other non-governmental prevention efforts have been kept at the level of 37% of the award amounts. In comparison with health department priorities before HIV prevention community planning (1993 and earlier) the following populations received increased priority for HIV prevention interventions after the advent of the initiative (January, 1994): men of color who have sex with men, women, women who are sex partners of IDUs, youth out of school, and racial/ethnic minorities.

### **Access to Voluntary HIV Counseling, Testing, and Partner Counseling Is Critical**

*Voluntary HIV testing* is an important part of comprehensive HIV prevention programs. However, testing alone will not result in behavior change, nor will it prevent transmission – sexual, drug-related, or perinatal. To have a chance of preventing HIV transmission and ensuring that necessary services and care are provided to infected individuals, the focus of HIV testing must be on counseling. Voluntary, rather than mandatory, HIV testing is recommended because it fosters the development of trust between patients and health care providers. A trusting atmosphere facilitates better understanding of what the test means for patients, their partners, and their families and helps ensure that they are linked to needed services and care.

*Anonymous HIV testing* should be available to increase options for individuals seeking to learn their HIV status. In this age of effective treatment, it is increasingly important for people to know their HIV status. Recent studies show that eliminating the availability of anonymous HIV testing services has a deterrent effect on some people's willingness to come forward for testing. People with legitimate concerns about discrimination or people who are unfamiliar with or distrust the public health system are able to gain access to the system through anonymous testing and subsequently receive referrals for needed treatment, care, or prevention services. Partner counseling also can be provided following anonymous testing, if requested.

*Partner counseling.* CDC considers voluntary, confidential notification of potentially exposed partners to be an essential component of a comprehensive HIV prevention program. Partner counseling is a primary prevention service with the following objectives:

- To provide prevention information to people who are at very high risk of becoming HIV infected, but who may be unaware of or misunderstand their risks
- To assist these individuals in obtaining HIV prevention counseling and voluntary testing, and referral
- To provide access to partners who are already infected to prevention and treatment services that can improve their health and quality of life

Partner counseling services can be provided in both anonymous and confidential testing sites. For areas lacking the resources to perform partner counseling services themselves, CDC recommends they provide the necessary training for conducting these services to physicians or hospitals that do HIV counseling and testing.

## **Reaching HIV-Infected Individuals and Linking Them with Care and Treatment Services Is a Priority**

The availability of effective drug therapies makes it more important than ever for HIV-infected persons to know their serostatus. Early recognition of their infection allows patients to consider treatment options that will keep them healthy longer and protect the quality of their lives. It also allows them to take steps to prevent transmitting the virus to others.

## **Comprehensive Efforts Are Needed for Reducing Drug-related Behaviors**

It is evident that drug use is exacerbating the spread of HIV throughout communities of color, particularly among African Americans and Latinos. In addition to the direct impact of injection drug use, many people are being infected through heterosexual contact with a drug-using partner or by having sex in exchange for money or drugs. Seroprevalence studies conducted in STD clinics and drug treatment centers continue to demonstrate the combined impact of STDs and drug use. Studies of HIV prevalence among patients in drug treatment centers and among childbearing women demonstrate that the heterosexual spread of HIV in women closely parallels the spread of HIV among injection drug users. The highest prevalence rate in both groups has been observed along the East Coast and in the South.

Preventing the spread of HIV requires a wide range of approaches, including programs to prevent initiation of drug use, to provide high quality substance abuse treatment options to drug users, to provide outreach services to drug users and their sex partners, to provide prevention services in jails and prisons, and to educate those at risk about preventive options. Prevention messages for drug users also must address the risks of sexual transmission, including the role and impact of other sexually transmitted diseases.

*Substance abuse prevention and treatment programs* are the key to slowing the spread of HIV in this population, and efforts in this area must be increased and strengthened nationwide. To further minimize the risk of HIV transmission, IDUs who continue to inject must have access to interventions that can help them protect their health. They must be advised to always use sterile injection equipment; warned never to reuse needles, syringes, and other injection equipment; and informed that using syringes that have been cleaned with bleach or other disinfectant is not as safe as using new, sterile syringes. Drug users not only need access to this information, but also the skills and support necessary for them to adopt and maintain safer behaviors.

*Increasing syringe availability as a prevention strategy.* To reduce the risk of HIV transmission through needle sharing, prevention strategies for IDUs who continue to inject drugs have included various approaches to increasing the availability of sterile syringes. In some communities, drug paraphernalia laws have been modified to exclude syringes, syringe prescription laws have been repealed, and pharmacy regulations and practice guidelines restricting the sale of sterile syringes have been changed. In other communities, syringe exchange programs have been established and are contributing to reductions in HIV transmission among drug users without encouraging the use of illegal drugs. Syringe exchange programs should also provide drug users with risk-reduction education and referrals to drug counseling and treatment and other medical services.

Having access to sterile injection equipment is important, but it is not enough. Better integration of all prevention and treatment services, including those for STDs and substance abuse, is critically needed. It is important to note that federal funds cannot be used to fund any type of syringe exchange programs.

HIV infection associated with substance abuse and resulting medical and health consequences have been reported among a variety of populations including African Americans, Latinos, Native Americans, and Asian and Pacific Islanders. Among minorities, young adolescents and women (particularly when using drugs during pregnancy) and men who have sex with men (due to methamphetamine abuse) are of greater concern for health care providers and policy makers. There appear significant disparities with regard to the access to and utilization of health care by the affected populations. The Department (CDC, HRSA, NIH/NIDA, and others) will need to support additional studies of (1) the epidemiology of drug use and HIV/AIDS and the nature and scope of their co-occurrences, correlates, and consequences; (2) linkages between drug use and HIV risk-taking; (3) interventions to prevent, reduce, or treat drug-related and HIV risk behaviors and associated medical and health consequences; (4) methodology to improve prevailing research paradigms for measuring, collecting data on, and analyzing drug use- and HIV-related behaviors among various minority populations and others; and (5) design and development of appropriate interventions (prevention and treatment- behavioral and pharmacotherapeutic).

Before successful interventions can be launched, research is needed to determine the incidence, prevalence, and underlying pathophysiology of medical and health consequences associated with HIV infection and substance abuse among minorities. A number of intervention initiatives (prevention and treatment, sometimes inseparable) followed by recommendations are briefly summarized below. It should be emphasized that the following activities and research be conducted among minority populations such as African Americans, Hispanics, Native Americans, and others in mind, and mention of these populations may not be repeated in all the descriptions.

*Epidemiologic Research on Drug-Related HIV/AIDS in Minorities.* The NIH supports several programs targeting minorities who are IDUs, including the Community-based Outreach Risk Reduction Strategy to Prevent HIV Risk Behaviors in Out-of-treatment Injection Drug Users program. Twenty-three sites have participated in the HIV Prevention Trial supported through this program. Participants have included 56.2% African American, 11.4% Puerto Rican, 9.0% Latino, 2.7% Native American, 0.3% Asian/Pacific Islander, 1.4% other Latino, and 17.2% Caucasian.

*Interventions for HIV-infected Drug Abusing Adolescents.* The NIH Adolescent Medicine HIV/AIDS Research Network (AMHARN) provides national leadership on key research policy and care issues facing HIV-infected youth. AMHARN brings together 20 principle investigators, doctors, and researchers at 15 sites through the United States. The sites are located in 13 major cities that are HIV epicenters. Project ACCESS, a social marketing campaign for HIV *uninfected* youth, reached through the social network of their HIV *infected* counterparts, was born from the AMHARN network. Project ACCESS is a unique partnership between social marketing/public relations entities and the AMHARN network investigators.

*Reducing the Risk of HIV Infection in Drug Addicted Women and Adolescents Through Behavioral Research.* Better interventions are needed to reduce the risk of HIV infection in drug-addicted women and adolescents. HIV infection in both populations is a serious and expanding problem, and few interventions are designed specifically to reduce unsafe sex and drug-using practices in these groups. The needs of women may be inadequately addressed in drug abuse counseling situations where women and men are frequently grouped together. Women may feel uncomfortable discussing some issues in these circumstances, especially regarding AIDS risk-reduction strategies. Behavior skills training interventions show promise in lowering risk for HIV infection among drug-addicted women and adolescents. Therefore, the development of gender-relevant interventions specifically designed to teach women assertiveness, communications skills, condom use skills, and other skills related to safer sexual relations would be beneficial. Innovative, developmentally appropriate strategies to reduce HIV risk in adolescents also are critically needed.

*Women's HIV Risk and Protective Behaviors.* The NIH has several important epidemiologic cohort studies of women in progress. Some examples include the Women and Infants Transmission Study (WITS) and the Women's Interagency HIV Study (WHIS), which focus on mother-to-infant transmission of HIV as well as manifestations of HIV infection and its sequella among women.

*HIV infection and Substance Abuse Among Men Who Have Sex With Men.* Drug-using men who have sex with men (DU MSM) are a highly diverse, vulnerable, and understudied population who may engage in HIV risk behaviors involving a variety of drugs and many sex partners over time. This group is a potential HIV "bridge" to multiple groups and subpopulations. Methamphetamine, in particular, is significantly more likely to be reported as a drug of choice by HIV-infected MSM who inject drugs than by male heterosexual IDUs because of its long-lasting stimulant effects and ability to enhance sexual arousal and stamina. Research is needed to integrate the epidemiologic knowledge about HIV risk behaviors and characteristics of DU MSM into innovative, theory-based behavioral and other interventions with special emphasis on minority populations. Concerted public health efforts are needed to understand both the epidemiology and the determinants of HIV risk and protective behaviors among DU MSM, and to develop, implement, and evaluate primary prevention and behavioral change interventions to prevent and reduce the incidence of HIV transmission in this population. Such efforts will facilitate the integration of behavioral therapies and risk-reduction interventions targeting DU MSM into the development and delivery of health services and drug treatment programs. The initiative will support or stimulate research on (1) the epidemiology of HIV-related risk and protective behaviors and health consequences among DU MSM; (2) HIV risk and protective behaviors of DU MSM relative to seroconversion, infection by other blood-borne viruses, and HIV-related morbidity and mortality; (3) innovative primary prevention and behavioral change intervention strategies that target diverse groups of DU MSM, including comparative evaluations of intervention outcomes and costs/benefits of community-based outreach, prevention, and treatment approaches to averting new HIV infections; (4) therapies for methamphetamine-abusing populations and on interventions aimed at eliminating high-risk behaviors associated with methamphetamine abuse; and (5) development and evaluation of new behavioral therapies, drug abuse treatment approaches, health services, and health care services delivery to DU MSM.

*Interactions Between Drugs of Abuse, Addiction Medications, and HIV Treatment Medications.* The continued use of illicit drugs during therapy for HIV/AIDS and opportunistic infections can modify the actions of therapeutic agents either by (1) direct pharmacological interactions or (2) indirect alteration of their pharmacokinetics or metabolic profiles by inhibition or induction of drug metabolizing enzymes. Also of importance is the biological fate of medications for the treatment of drug addiction and the interactions of these compounds and their metabolites with both drugs of abuse and therapeutics for HIV. Treatment drugs (e.g., methadone) for addicts interfere with the treatment medication for HIV. This is especially important in light of the new dual or triple drug therapies that may use the same or equivalent metabolizing and excretion systems, as has already been documented with AZT. Future studies should include understanding the basis of these interactions, the long-term consequences, how and when possible alternate treatment schedules should be developed, and the approaches to ascertaining how modified therapies are to be identified, structured and monitored. This initiative will support basic animal and human clinical research on aspects of these drug-on-drug interactions and how this may affect the treatment of HIV/AIDS in drug-abusing populations.

*Expanding the Integration of HIV/AIDS and HIV Prevention Services in Drug Abuse Treatment.* Drug abuse service delivery systems continue to contend with HIV-positive and AIDS patients as well as patients at high risk of becoming infected with HIV. The successful drug treatment of HIV-infected and

AIDS patients requires greater integration of medical services with critical support services. Meeting the continuing high demand for these types of services requires better training and supervision of service delivery staff. Staff who deal with these patients may also need different types of support, including group and individual counseling, to manage the emotional toll of working with sick patients in an increasingly restricted system. This research would include organizational and management strategies that focus on (1) training for administrative and counseling staff related to HIV and AIDS services; (2) management models that increase service integration across programs, particularly in the criminal justice system, to improve continuity of care; (3) how primary care can be incorporated into community and institutional treatment settings; and (4) the impact of programming for HIV/AIDS services on treatment outcomes, program performance, and community commitment to treatment.

*Improving Engagement and Relapse Prevention Interventions to Reduce HIV Risk.* Enhancing strategies aimed at engaging clients and improving relapse prevention skills can have a significant impact on the effectiveness of drug abuse treatment in general and for HIV risk reduction specifically. Research should focus on the significance of early treatment dropout and relapse in contracting and spreading HIV and other related infectious diseases. HIV risk should be assessed at baseline as well as during treatment and post-treatment. The goal should be to improve patient engagement in drug abuse treatment and commitment to reduce behaviors that can lead to becoming infected or transmitting the infection to another party. Research supported under this initiative will help (1) identify those strategies that help engage patients and improve early retention rates; (2) improve relapse prevention skills during and after treatment; (3) train staff to incorporate assessment techniques aimed at understanding patient motivation for change and commitment to treatment; and (4) identify technologies that help transfer proven engagement and relapse prevention technologies in packages that can be easily incorporated by clinical staffs.

*Reducing AIDS Risk Behaviors in HIV Positive Drug Users.* For HIV-positive drug addicts in treatment, the development of interventions to provide skills for protecting their own health and reducing the risk of transmitting HIV to others is critical. Many in this population have unique medical and emotional needs that must be addressed before they will be receptive to learning risk-reduction strategies. Many HIV-positive patients show impairment in such areas as information processing, verbal memory, procedural learning, concentration, and problem solving, especially in the advanced stages of HIV disease. Moreover, long-term drug use and psychiatric disorders can additionally contribute to the cognitive deficits experienced by some HIV-positive patients, as can medications for the treatment of HIV. Hopelessness, anticipatory grief reactions, and a multitude of psycho-social stressors may negatively influence their readiness to change their behavior. Additionally, some HIV-infected persons may be less motivated to reduce their risk behaviors since they are already infected. However, if they continue to practice high-risk behaviors, not only will they risk spreading HIV to others, but they may become reinfected with other strains of the virus themselves, possibly inducing more rapid disease progression. Risk-reduction interventions for HIV-infected patients that address coping with their disease and improving daily living skills will enhance their quality of life and possibly reduce the chances of spreading their infection to others.

*Reducing the Risk of HIV Infection in Drug Addicts Through Behavioral Research.* More extensive behavioral research is needed in the area of reducing high-risk behaviors in drug-addicted populations seen in treatment and in primary health care settings. Currently there are no empirically validated AIDS risk-reduction counseling strategies for HIV/AIDS patients who abuse drugs. Treatment researchers are hesitant to provide HIV-risk reduction approaches that may not be effective. Brief behavioral interventions to reduce HIV risk are also needed for drug addicts seen in primary health care settings. Drug addicts are at increased risk for HIV/AIDS (or already infected) when seeking health care for medical problems that may

be related to their drug abuse and associated health risk behaviors. For these individuals, contact in primary health care settings may provide unique and important opportunities for intervention. Little is known about interventions in office-based and other health care settings that are aimed at reducing behaviors that put these individuals at risk for HIV acquisition or transmission of HIV/AIDS to others. Earlier intervention in health care settings may increase recruitment into drug treatment for individuals at high risk. There is a tremendous need for the development of a spectrum of effective interventions to reduce AIDS-risky behavior in treatment and in primary health care settings. Since these individuals differ in variety of factors, such as drug of choice (and route of administration), types of AIDS risk behaviors, psychiatric co-morbidity and socio-cultural background, there is a need for developing several strategies that can be used in various settings. NIDA will support this effort to encourage behavioral therapy research to reduce AIDS risk behaviors in those seen in treatment and in office-based and other health care settings. Expanded research in these areas will reduce HIV infection in drug addicts at risk.

*Cross-National Research on HIV Intervention among Drug Users.* Of the 120 or more countries that report injection drug use, 80 have documented drug injection as a major risk factor for HIV transmission. The rates of HIV transmission among injectors throughout the world has been shown to vary considerably across countries. In some areas the spread of HIV has occurred extremely rapidly whereas other areas report very stable and low seroprevalence rates. Although the primary routes and specific mechanisms of transmission of HIV among injection drug users have been found to be similar across regions of the world, different countries have reacted differently to this public health threat, and with different degrees of success. This initiative will improve the knowledge base on the similarities and variations in drug use patterns and HIV risk behaviors (drug and sexual risks) in different national and regional environments. A cross-national research program has the potential to help us understand the effectiveness of intervention (prevention/treatment) efforts in different countries and to develop a global strategy for dealing with HIV transmission in IDUs. This research will explore cross-national studies through a range of interventions (community-based outreach, needle exchange programs, drug treatment as HIV prevention, counseling and testing, partner notification, and network-based strategies), behavior change, and the prevention of HIV. Through this effort, studies can be supported that identify which interventions work and how (e.g., by examining the role of intervention components), and which behaviors are most affected, by how much, among which populations, and for how long a period of time. The research process will also address the issue of sustaining community-based interventions after the research phase has been completed. In addition, differences across countries in social structures, gender and social/cultural relationships, dynamics of risk networks, and the high-risk settings in which drug use occur should provide for comparative analysis of the relative effectiveness of these interventions.

*Global Research Network on Drug Abuse and HIV Intervention (Prevention/Treatment).* The overall objective is to establish a self-sustaining global communications network for rapid international communication, dissemination, and utilization of HIV/AIDS epidemiology and prevention/treatment research information. Interim steps to achieve this goal include a 2-day international meeting in 1999 to provide a forum for HIV intervention researchers and scientists to exchange and interpret research findings from intervention studies that target injection and non-injection drug users at high risk for HIV and other blood-borne diseases; translate and effectively disseminate research findings into good international practices to slow the spread of HIV and to ensure that usable information is rapidly communicated for utilization; stimulate cross-national studies of the applicability and effectiveness of strategies to prevent HIV and other blood-borne diseases; and facilitate collaborative efforts and minimize unnecessary duplication of research efforts at the international level. Approximately 50 international HIV prevention researchers and collaborators will be invited to attend from various countries and representative of the WHO Regions. The countries include:

Australia; Canada; Brazil; China; Germany; Hungary; India; Italy; Kazakstan; Malaysia; Mexico; Netherlands; Nigeria; Pakistan; People's Republic of China; Portugal; Slovak Republic; South Africa; Spain; Switzerland; United Kingdom; United States of America, and Vietnam.

In addition, it may be necessary to establish the global research network as a telecommunications system which will link network members and permit the rapid exchange of HIV intervention/ prevention and drug abuse information; consultations among HIV experts, collaborators, and practitioners from around the world, who can both solicit and provide expert advice on HIV intervention strategies and conditions that apply in other countries; dissemination of data about emerging trends and promising interventions; and informal "virtual" meetings and chat-room sessions.

In summary, effectively fighting the epidemic among persons of color who use drugs requires

- more extensive use of scientifically supported prevention interventions for IDUs,
- more research to help fine-tune these interventions for communities of color,
- and simply *more prevention services* for communities of color across the board.

### **Care and Treatment**

For the first few years of the HIV/AIDS epidemic, effective treatment options for HIV disease were not available. Over the last decade, preventive therapies for opportunistic infections were developed and have shown considerable success in keeping HIV-infected persons healthier. Also, zidovudine (ZDV, or AZT), the first and for several years the only antiretroviral medication, led to temporary improvements in health but had limited long-term impact on morbidity and mortality. With the introduction of multiple new antiretroviral agents since 1995, combination therapy is now the standard for the medical treatment of HIV/AIDS.

Therapy with two or more agents can be effective in patients as judged by reduction in blood levels of HIV, resolution of HIV-related symptoms, prevention of opportunistic infections, delaying progression to AIDS, and reducing mortality. However, limitations of these promising therapies include adverse drug reactions, difficulty in adhering to complicated dosing schedules, and high cost. In addition, patients' lives often are affected by other factors that can limit their ability to procure these drugs or adhere to the treatment regimens, such as active substance abuse, mental illness, incarceration, migrant or homeless status or other isolated living situation, sociocultural alienation, or poverty. For these reasons, all populations do not benefit equally from these new treatments. Studies have shown that people of color with HIV/AIDS are less likely to be receiving medical care, and those in care are less likely to be receiving a protease inhibitor (a cornerstone of antiretroviral therapy) or prophylaxis against opportunistic infections such as *Pneumocystis carinii* pneumonia.

Helping communities of color will involve fostering good experiences with health professionals who maintain trust and provide caring, respectful health services. The provision of high-quality medical care and related supportive services to all persons with HIV/AIDS is a central component in the effort to eliminate disparities in morbidity and mortality from this disease.

### **Activities to Improve Medical Care**

*Increase in medical facilities caring for HIV/AIDS.* The disparities in HIV/AIDS morbidity and mortality between members of racial/ethnic groups arise, in part, from poor access to care. Medical facilities specializing in HIV/AIDS care exist in high prevalence, urban areas. Many such clinics offer care regardless of a person's ability to pay. However, a high percentage of such clinics operate at capacity and/or are not easily

accessible due to transportation barriers. In rural areas, HIV/AIDS care from experienced providers is often not available at all, regardless of ability to pay. One option is to construct a nationwide HIV/AIDS health-care infrastructure. This is unlikely to be financially feasible or sustainable. A more attractive option is to better use the existing healthcare infrastructure to address the treatment needs of persons with HIV/AIDS.

In the private sector, more incentive and training must be provided to community-level practitioners to care for persons with HIV/AIDS. Since the minority of persons with HIV/AIDS are supported by a private third-party payment system, there will be limits to how much additional medical care can be provided by the private sector. In contrast, the public health system has a large role to play in increasing the penetration of HIV/AIDS care into all segments of the population.

Publicly funded community health centers are the federal government's instrument for providing medical care to underserved persons in the United States. Of the more than 2,500 such public health clinics, many are already providing quality HIV/AIDS care in poor, rural, and minority communities. However, a substantial number are not because of cost, stigma, failure to perceive need, or lack of expertise in HIV/AIDS care. The capacity of federally funded public health clinics can be enhanced to provide HIV/AIDS medical care to more racial and ethnic minorities through the appropriate targeting of financial support and technical assistance.

*Increase in RWCA Title III Grants.* Recognition of the role of medical care in HIV/AIDS is the central focus in the Ryan White Care Act Title III program, the section of the Ryan White Care Act which provides grants directly to providers of HIV/AIDS services (as compared to the RWCA Titles I and II, which provide grants to cities and states, respectively). The Ryan White Title III program supports a primary care model for HIV/AIDS, and stipulates that a minimum of 50% of the funds go directly for provision of medical services. In this way, HRSA's Bureau of HIV/AIDS is able to directly target medical services to communities of need.

*Increase the number of medical care providers of HIV/AIDS care.* As medical treatment has assumed a central role in the care of persons with HIV/AIDS, and the treatment has become more difficult and complicated, the role of medical providers has assumed a greater importance. There has been a retreat from the previously supported view that HIV/AIDS should be treated by all clinicians. Data now show that patient outcome improves with the experience of the medical care provider in HIV/AIDS. Since the majority of those needing HIV/AIDS care are those traditionally underserved by medical care, there is a need for HIV/AIDS "specialists" in medically underserved communities. The placement of health care providers in such communities is traditionally the role of HRSA's National Health Service Corps (NHSC). A proportion of these providers should be contributing to the urgent need for improved access to HIV/AIDS care among racial and ethnic minorities.

*Increase education of providers in quality HIV/AIDS care.* The complicated regimens for HIV/AIDS have forced providers to develop specialized expertise in the care of HIV/AIDS patients. The consequences of poor quality care are the development of viral resistance, loss of ability to treat HIV infection in an individual, and possible transmission of resistant virus to others. To set standards for the use of these complicated drug regimens, the Public Health Service has issued guidelines, and updates them regularly, for the use of anti-retroviral therapy in adults, adolescents, and children. The education of medical providers is conducted by a variety of public and private organizations. A substantial amount of the training in these guidelines, and other issues in the medical management of HIV/AIDS, is provided by HRSA through the



AIDS Educational Training Centers (AETCs). These 15 Centers, distributed geographically across the United States, have responsibility for providing clinical training in all 50 states. Providers of care to minority clients are to be targeted by the AETCs. However, several quality of care measures, such as prevalence of prophylaxis against pneumocystis pneumonia, the taking of a protease inhibitor, and the absence of monotherapy all suggest that there is a lag between the introduction of these interventions in the general medical community and the penetration into minority populations. Thus, more aggressive and targeted education for providers of care for racial and ethnic minorities must be a priority.

*Improve medical care of incarcerated persons living with HIV/AIDS.* Minorities are disproportionately represented among incarcerated populations. The amount and type of medical care available to inmates varies by prison, county, and state. No standards of medical care exist to ensure access to quality HIV/AIDS care for inmates. In addition, the medical needs of prisoners are often not adequately addressed upon their release from prison. Oftentimes, prisoners are given one to two weeks of medication, and left on their own to negotiate the medical care system. Better linkage between medical care in and out of prison is a priority to ensure better HIV/AIDS treatment for racial and ethnic minorities.

*Increase availability of substance abuse treatment.* Substance abuse is a major risk factor for HIV acquisition. Active substance abuse also has serious implications for the treatment of established HIV infection. The benefit of HIV/AIDS treatment is severely compromised by poor adherence. Numerous studies suggest that adherence to therapy is emerging as the single greatest predictor of successful HIV/AIDS treatment. Active alcohol and drug abuse have a direct and strong negative impact upon the ability of a person to take the complicated regimens as prescribed. In addition, adverse drug reactions may be compounded or clouded by active substance abuse. The availability of effective, comprehensive substance abuse treatment is a major contributing factor to successful HIV/AIDS care, but is still not a reality for those who cannot pay for it. Substance abuse treatment must consist of detoxification, treatment of co-morbid conditions, (e.g. mental illness, pain syndromes), maintenance treatment and relapse prevention. Such treatment is also often highly dependent upon social support issues, such as housing and transportation.

*Improve mental health services provided to persons living with HIV/AIDS.* Mental illness can be an antecedent or a result of HIV/AIDS. The most common manifestations are depression, bipolar disease, and anxiety disorders. More severe illness such as schizophrenia and personality disorder are also seen. It is not clear whether mental illnesses are more common among racial and ethnic minorities with HIV/AIDS; however, access to treatment for these conditions is limited as compared with the general population due to the paucity of publicly-funded mental health services. Since these illnesses can have significant impact upon the ability of persons to adhere to the medical therapy for HIV/AIDS, treatment of mental health conditions is a crucial element of HIV/AIDS care. As with substance abuse, mental health treatment is most effective when provided in collaboration with other medical services.

*Expand ADAP program.* A formidable barrier to the equitable distribution of HIV/AIDS care, given the disproportionate number of persons with HIV/AIDS living in poverty, is the high cost of pharmaceuticals. The cost of combination therapy (the standard at this time is three or more drugs simultaneously) is roughly \$10,000 per year, representing approximately 80% of the average yearly cost of caring for a person with HIV (this percentage decreases as persons develop AIDS and incur more non-drug costs). Expenditure on medication, however, yields tangible savings in other potential costs, such as hospitalization, emergency department visits, and treatment of opportunistic infections. Thus, medical treatment of HIV/AIDS is cost-effective. Despite this knowledge, access to expensive drug therapy is still limited for some who cannot pay. The AIDS Drug Assistance Program (ADAP) is funded under Title II of the Ryan White CARE Act.

ADAP, funded at \$285.5 million in FY 1998, covers HIV/AIDS-related pharmaceuticals to persons not able to procure these medications through private insurance or Medicaid. ADAP eligibility is defined by each state. In states where ADAP eligibility is more restrictive, there are still patients unable to access combination therapy for HIV/AIDS. Racial and ethnic minorities are less likely to be taking combination therapy. The degree to which this is due to inability to purchase medication is not known. However, further investigation of access to pharmaceuticals through the ADAP should be conducted, and any deficits in access for racial and ethnic minorities should be corrected.

*Improve early diagnosis of new HIV infections.* For those who are infected, knowledge of serostatus is critical for preventing additional people from becoming infected. Research indicates that a person's knowledge of their serostatus differs by the individual's exposure, general knowledge about risk factors for HIV/AIDS, and physicians' behavior. In the 1980s, because the association of AIDS with homosexual behaviors was known and widely disseminated, gay men increased their voluntary testing for HIV. In the 1990s, more pregnant women were tested in response to campaigns to increase knowledge of perinatally transmitted HIV infection, and testing among drug users increased as a result of public health efforts to communicate the HIV risk associated with sharing needles. Increasing knowledge of serostatus and reducing HIV/AIDS in communities of color will require the same kind of targeted interventions. The availability of counseling and testing programs (including anonymous testing) and linkages with partner counseling and referral services must be improved in racial/ethnic minority communities. CDC estimates that 20% of new HIV infections could have been prevented through confidential testing and counseling programs that are linked to partner notification programs.

*Participation in clinical trials.* To ensure that communities of color benefit from the recent medical advances, it is also important that people from all racial and ethnic groups participate in clinical trials. Women, patients of color and drug users, however, are significantly less likely to have ever participated in an AIDS clinical trial than other HIV/AIDS patients. Reasons for nonparticipation include less knowledge of clinical trials and unfavorable opinions of clinical research.

*Perinatally Acquired HIV Infection.* Recent studies have identified a lack of prenatal care as the primary reason why some pregnant women do not receive HIV counseling and testing and, if infected, do not have the benefit of ZDV therapy for reducing the risk of transmitting HIV infection to their infants. Women who use drugs are especially likely not to receive prenatal care. We must increase the proportion of drug-using pregnant women who receive prenatal care that includes routine counseling and voluntary testing for HIV infection, especially in communities of color.

The National Institutes of Health (NIH) continuously reviews its AIDS research programs and implements program-specific initiatives to ensure that HIV-infected individuals from the most at-risk populations for HIV/AIDS are enrolled in federally sponsored AIDS clinical trials and natural history and epidemiology studies. NIH has and will continue to implement specific program initiatives to provide training of minority scientists in all areas of AIDS research as well as support outreach and public educational efforts to the affected and HIV-infected communities. NIH supports a diverse network of clinical trials programs, which includes the Adult AIDS Clinical Trials Group (AACTG), the Pediatric AIDS Clinical Trials Group (PACTG), the Terry Bein Community Programs for Clinical Research on AIDS (CPCRA), Studies of the Ocular Complications of AIDS (SOCA), the Neurologic AIDS Research Consortium (NARC), and the AIDS Malignancy Consortium (AMC). More than 50,000 patients have been enrolled to date in HIV-sponsored clinical studies, which have involved the evaluation of over 200 agents. As of December 1999, minority enrollment in HIV-supported AIDS clinical trials remained in excess of 60 percent, the approximate proportion of all AIDS cases. Specific programs have been implemented to recruit minority popula-

tions into AIDS-related research including: fostering collaborations between the Centers for AIDS Research and Research Centers in Minority Institutions for the conduct of biomedical research at minority institutions; recruiting minorities into studies on AIDS-related malignancies in the AIDS Malignancy Consortium; and targeting enrollment of minority injection drug users (IDUs) into the Community-Based Outreach Risk Reduction Strategy to Prevent HIV Risk Behaviors in Out-of-Treatment IDUs program and other prevention trials. NIH also supports specific programs that target the training of minority researchers as well as outreach and public education programs in minority communities. These efforts include: the AIDS Clinical Trials Infrastructure in Minority Institutions which serves to enhance the training and number of minority investigators involved in AIDS Clinical Trials Group research, as well as the number of minority participants in clinical studies; the Regional Technology Transfer Program which provides bench to bedside information targeting community health care professionals, especially in minority and rural communities; and an outreach program to train health professionals in Historically Black colleges and Universities for accessing AIDS-related information resources. The CPCRA program has existed since 1989. This network of community based providers conducts clinical protocols permitting access to a large number of patients whose demographic characteristics reflect those of the evolving epidemic. These networks have provided special services to encourage the enrollment and retention of affected populations in clinical trials including obstetric/gynecology care, transportation, child care, special hours of operation, and other services to meet patient's special needs.

### **Health Education and Risk Reduction: Individual and Group Interventions**

Health education and risk-reduction activities are targeted to reach persons at increased risk of becoming infected with HIV or, if already infected, of transmitting the virus to others. The goal of health education and risk-reduction programs is to reduce the risk of these events occurring. Activities should be directed to persons whose behaviors or personal circumstances place them at risk. Street and community outreach, risk reduction counseling, prevention case management, and community-level intervention have been identified as successful health education and risk-reduction activities. (See summary of NIH Consensus Development Conference statement that begins on page 40.) *We must make much more extensive use of what already has been shown to be effective.*

*Street and Community Outreach.* Street and community outreach can be described as an activity conducted outside a more traditional, institutional health care setting for the purposes of providing direct health education and risk reduction services or referrals. However, before conducting any outreach activity in a community, an agency must define the specific population to be served and determine their general needs. Based on this definition and determination, an agency can then decide appropriately where to conduct intervention efforts. Street and community outreach may be conducted anywhere from a street corner to a pool hall, from a parish hall to a school room. To determine the setting, an agency need only decide that the setting is easily, readily, and regularly accessed by the designated client population.

While street and community outreach can be complementary service components of a single agency, some agencies, based on needs assessment findings and staff capacity, may choose to provide one service and not the other. Street outreach and community outreach can also be "stand alone" pieces.

*Street Outreach.* Street outreach commonly involves outreach specialists moving throughout a particular neighborhood or community to deliver risk-reduction information and materials. The fundamental principle of street outreach is that the outreach specialist establishes face-to-face contact with the client to provide HIV/AIDS risk reduction information and services.

Effective street outreach staff:

- know the target group's language
- have basic training and experience in health education
- are sensitive to community norms, values, cultural beliefs, and traditions
- have a shared identity with the population served, stemming from shared common personal experiences with the group
- are trusted by the group they serve
- act as role models to the clients they serve
- advocate for the population served
- act as liaisons between the community and the agency
- are informed about community resources and use them.

Street outreach is not simply moving standard agency operations out onto the sidewalk. A number of specific issues are unique to the delivery of services through this type of outreach and must be considered before instituting a program of street outreach. These matters are usually addressed in an agency's street outreach program plan.

*Community Outreach: Workshops and Presentations.* Workshops and presentations are typical activities of community outreach. Because they usually follow lecture formats, they can be highly structured health education and risk-reduction intervention efforts. While they supply important opportunities to disseminate HIV/AIDS prevention information, their impact on behavior change is limited because they are usually single-encounter experiences. Although they provide crucial technical information that raises awareness and increases knowledge and may be a critical first step in the change process, the information alone is usually inadequate to sustain behavior change.

To maximize their benefit, workshops and presentations should be planned carefully with knowledge goals and objectives specified before the individual sessions. To the extent possible, presenters should be informed about the setting where the workshop or presentation will take place, as well as the composition and knowledge level of the anticipated audience.

### **Comprehensive Efforts Are Needed for Reducing Sexual Risk Behaviors**

In all prevention activities, CDC supports the incorporation of prevention messages and programs that strongly emphasize that young people should postpone sexual activity, and that sexually active adults should maintain a monogamous relationship with an uninfected partner. However, some young people and adults will still engage in sexual intercourse that puts them at risk for HIV and other sexually transmitted diseases (STDs). To ensure these individuals acquire the knowledge and skills necessary to protect themselves from HIV, CDC also supports prevention messages and programs that encourage consistent and correct use of latex condoms among those who are sexually active. Research has conclusively shown that latex condoms are highly effective barriers to HIV and many other sexually transmitted diseases when used consistently and correctly.

*Condom availability as a prevention strategy.* Individuals in some populations, especially sexually active young people, may experience problems accessing condoms because of several factors, including cost, convenience, and embarrassment. For these individuals, the fact that condoms are not readily accessible may be a significant barrier to consistent use. To eliminate this barrier, many local communities actively support programs that make condoms available to populations most vulnerable to HIV infection, including

sexually active young people. Research shows that providing access to condoms can increase their use among some sexually active young people. Along with increasing access to condoms, we also need to implement interventions shown to be effective at giving people the *skills* they need to use condoms correctly and consistently. Despite some fears to the contrary, research clearly demonstrates that young people who participate in comprehensive HIV prevention programs that include access to condoms are no more likely to initiate or increase sexual activity than other young people.

*Treating other STDs.* There is strong evidence that other sexually transmitted diseases (STDs) increase the risk of HIV transmission. Communities of color suffer disproportionately high rates of many STDs. The sexual spread of HIV in the United States has paralleled that of other STDs. The geographic distribution of heterosexual HIV transmission closely parallels that of syphilis and gonorrhea, with the highest rates of syphilis and gonorrhea being concentrated in the South, the same part of the country with the highest HIV prevalence among women of childbearing age. Again, this interface must be addressed and STD prevention and treatment must be acknowledged as a viable HIV prevention intervention. STD treatment reduces the spread of HIV.

*Special emphasis on young gay men.* Issues specifically related to gay men, especially gay men of color, must be addressed. The continued high rates of HIV prevalence among young gay men, and young gay men of color in particular, demonstrates the critical need to provide this population with the information, interventions, skills, and support required to change and sustain positive behavior. The denial and homophobia that exist within communities of color must be addressed to ensure that this particular population's prevention needs are also met.

No single approach, prevention counseling and health education, abstinence promotion, condom education, condom availability, STD treatment, can eliminate HIV. Each affected community can best determine which combination of approaches will be most appropriate and effective for preventing HIV infection under local circumstances.

### **Comprehensive Programs for Youth Are Essential**

*School-based programs.* It is estimated that half of new HIV infections in the United States, about 40,000 annually, are among people younger than 25. Prevention activities and interventions that begin well before young adulthood are desperately needed to stem this tide. To that end, CDC supports comprehensive school-based HIV prevention programs. CDC does not require any specific curriculum, but recommends that the scope and content of school health programs be locally determined and consistent with parental and community values. At the same time, CDC has identified curricula that have credible evidence of reducing health risk behaviors among youth. CDC also provides resources, including training, to ensure that the interventions are available for those who want to use them.

*Programs for out-of-school youth.* Many youth at very high HIV risk, such as homeless or runaway youth, juvenile offenders, or school drop-outs, can only be reached through intensive community-based programs. Integrating HIV prevention programs with ongoing community efforts to provide shelter, medical care, or other services to out-of-school youth is essential.

## **Improved Prevention Programs in Correctional Facilities Are Critical**

Correctional facilities are critical settings for monitoring the cutting edge of the HIV/AIDS epidemic and for addressing the problem of elevated rates of TB, STDs, hepatitis, and other infectious diseases. Inmate populations probably represent the largest concentration of persons infected with, or at high risk for, HIV because of their drug use and unsafe sexual behaviors. Furthermore, short stays and high recidivism rates result in a substantial number of high-risk individuals who circulate between correctional facilities and their communities, most often, communities that are already beset by poverty, drug use, violence, and disease. It is imperative that correctional facilities offer effective programs for disease screening, treatment, and prevention.

Correctional facilities offer significant opportunities for intervention. Their controlled settings allow efficient access to inmates for the delivery of prevention programs. However, the opportunity to provide comprehensive education and prevention programs in prison, jails, and juvenile facilities, has been missed to a great extent. CDC is working to improve community health through improved access to HIV, STD, and TB health care and prevention services within correctional settings and transitional programs in communities.

## **Sound Public Health Policy Must Be the Goal**

Sound public health practice should be carefully considered in all policy and program discussions about HIV prevention and treatment programs. Decisions about implementing new or revised policies on either the state or national level must consider the public health implications of proposed policies. Program designers and policy makers must ensure that the approaches undertaken will be the most effective in reducing HIV transmission and saving lives.

Given the wealth of information that now exists about what biomedical and behavioral approaches work best in HIV prevention, the immediate challenge is to utilize that information to design effective tools and interventions for communities of color to ensure that the success experienced by other communities is extended to all communities. Nothing less is acceptable.

## **Capacity Building**

“Capacity development is the process by which individuals, organizations, institutions and societies develop abilities (individually and collectively) to perform functions, solve problems and set and achieve objectives . . . It is a continuous learning and changing process. It emphasizes better use and empowerment of individuals and organizations. And it requires that systemic approaches be considered in devising capacity development strategies and programs.”

The goal of capacity building is to foster self-sufficiency. Capacity building is about teaching critical skills. Based on the Friearian concept of critical thought, capacity building ideally is a process of the “capacity builder” fostering the development in a recipient of capacity building processes with the self-sustaining ability to improve programs, processes, and ultimately, outcomes.

## **Levels of Capacity Building**

### ***Organizational Capacity Building***

Organizational capacity-building is an increase in the core competencies that contribute to an organization's ability to design and implement an effective HIV intervention and to sustain the infrastructure and resource base necessary to develop and support the intervention. Some examples of core competencies for organizational capacity are management of program finances, conducting effective HIV interventions, personnel management, preparation of grant applications to obtain resources, conducting intervention evaluations, and cultural competency development.

**Organizations** - Aspects of capacity building with an organization include the following:

- Training
- Skills-building
- Technical Assistance\Support
- Twinning
- Provision of Resources
- Technology Transfer

### ***Community/Environmental Capacity Building***

Community/Environmental capacity-building is an increase in the core competencies that contribute to the community's ability to address HIV/AIDS. Capacity building for communities/environmental addresses coalition development, access to resources, economic development, policy, governance and community leadership development.

**Communities/Environment** - Methods of capacity building with communities/environment may include:

- Provision of Resources
- Addressing Policy
- Information Dissemination
- Education and Training
- Facilitation of Community Discourse

### ***Individual Capacity Building***

Individual capacity building involves improving or addressing critical thought, self actualization, knowledge base and professional development.

**Individuals** - Methods of capacity building with individuals include:

- Training
- Skills building
- Technical Assistance/Support
- Knowledge/Education (Information Exchange)

## **Technical Assistance Assessment and Plan**

An HIV technical assistance needs assessment entails identifying needs of the health department, community planning(s), and community-based providers in the areas of program planning, implementation, and evaluation, and a plan of activities that addresses the technical assistance needs.

The capacity-building delivery mechanisms include information transfer, skills building, technical consultation, technical services, technology transfer and funding.

**Information transfer** - the provider collects, packages, and disseminates information to the recipient. The information may be disseminated through newsletters, technical reports, conference announcements, list serves, batch faxes, and maintenance hotlines.

**Skills Building** - the provider facilitates the enhancement of skill sets of key personnel whose activities contribute to increasing the capacity of an organization. These skills sets are delivered through training of staff, board, trainers, volunteers, community members, and opinion leaders.

**Technical Consultation** - the provider delivers expert advice to key personnel on how to accomplish a task or series with the intent that the activity will be carried out by the recipient of the advice. Technical consultation may be provided telephonically, on site, electronically, or written documents.

**Technical Services** - the provider carries out a task or series of technical tasks for the recipient that result in increased capacity. These technical services may relate to facilitating or implementing operational, managerial, technological, programmatic, administrative, or governance systems.

**Technology Transfer** - the provider facilitates recipient access to products, methodologies, or techniques that increase capacity. Technology transfer may be accompanied by skills building, technical consultation, or technical services. Some examples are computer technology that allows INTERNET access, development of a training curriculum, and the adoption of a new intervention.



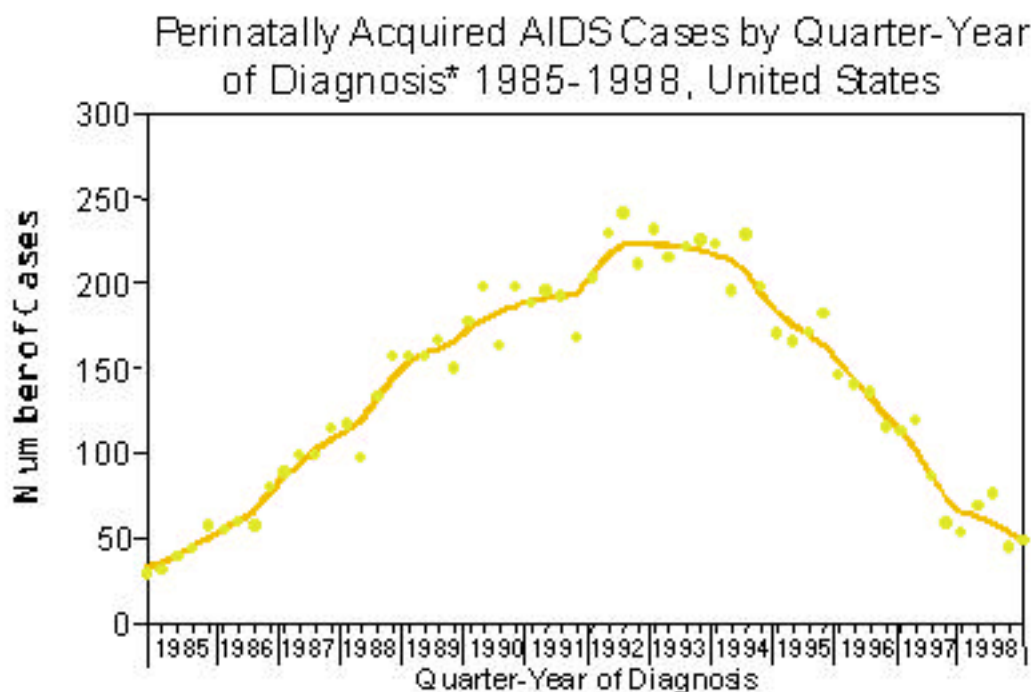
## *Implementing a Comprehensive and Effective Community Response to HIV/AIDS in Communities of Color*

### **EFFECTIVE INTERVENTIONS**

Both biomedical and behavioral HIV prevention programs have been shown to be effective in reducing HIV transmission. Hence, important tools are available for slowing the spread of HIV infection. A major issue remains: *how to refine these interventions to make them culturally relevant and appropriate in communities of color.*

#### ***Biomedical Interventions***

- ***Preventing Infections in Infants.*** During the early 1990s, before perinatal preventive treatments were available, an estimated 1,000-2,000 infants were born with HIV infection each year in this country. Today, the United States has seen dramatic reductions in mother-to-child, or perinatal, HIV transmission rates. These declines reflect the widespread success of Public Health Service (PHS) recommendations made in 1994 and 1995 for routinely counseling and voluntarily testing pregnant women for HIV, and for offering zidovudine (AZT, also called ZDV) to infected women during pregnancy and delivery, and to the infant after birth. Important challenges remain in ensuring that communities of color gain equal access to this intervention.



\* Adjusted for reporting delays and redistribution of NIAID, data reported through December 1999

- *Prophylaxis for opportunistic infections.* Medical interventions to prevent the opportunistic infections common in HIV-infected persons have been very successful over the last decade. Since 1987, the percentage of HIV-related deaths associated with many opportunistic diseases has decreased, especially for pneumocystosis, cryptococcosis, and candidiasis. To obtain maximum benefit from prophylaxis against opportunistic infections, it is critical that HIV-infected persons learn of their HIV infection and obtain appropriate medical care as early as possible. Again, the challenge of ensuring access to counseling, testing, and treatment is an issue in many communities of color.
- *Combination drug therapies.* Many people, but not all, have had great success with new highly active antiretroviral therapies (HAART) and as a result, there have been declines in both the number of newly reported AIDS cases and deaths. The success of HAART is good news for the people living longer, better lives because of it, but the availability of treatment may lull people into believing that preventing HIV infection is no longer important. This complacency about the need for prevention adds a new dimension of complexity for both program planners and individuals at risk. Also, there are concerns that today's new medical treatments, while showing great success in keeping many HIV-infected people healthy longer, are still not working for everyone, often have serious side effects, and are extremely expensive. Newer and even better treatments for HIV disease are anticipated and welcomed. In the meantime, the major challenge will be to ensure that all HIV-infected persons, especially in communities of color, have an equal opportunity to benefit from the most effective medical therapies.
- *STD treatment for preventing HIV infection.* The United States has the highest rates of STDs in the industrialized world, with some subpopulations experiencing even higher-than-average incidence and prevalence. Sexually active adolescents in general have a high prevalence of chlamydia, and African American women aged 15-19 years and men aged 20-24 years have high rates of gonorrhea. Reported rates of primary and secondary syphilis in this country are approximately 50-fold higher among young African Americans than Whites. STD cofactor effects appear to play a role in the increasing HIV epidemic among heterosexuals, especially young African American women. While researchers have documented an important link between the treatment of sexually transmitted diseases and reduction in the spread of HIV, the challenge continues to be the development of and access to interventions that provide STD screening and treatment.

## ***Behavioral Interventions***

Today, there is more comprehensive evidence than ever that HIV prevention programs are effective. Many studies indicate that behavioral interventions can contribute to changes in personal behavior that reduce risks of infection, and that these changes are sustained over time.

## **Prevention Research Synthesis**

CDC researchers have assimilated and analyzed all available studies to date that evaluate the impact of prevention programs and have created through the Prevention Research Synthesis Project (PRS), the *Compendium of HIV Prevention Interventions with Evidence of Effectiveness*. The *Compendium* incorporates all well-conducted evaluations of the full range of HIV prevention programs, from school-based education to street outreach for injection drug users. Findings from examining 46 U.S. studies of more than 18,000 individuals indicate that participants significantly reduced their risk behaviors following the program interventions. Examples of effective interventions outlined in the *Compendium* are included below:

## **Examples of Effective Interventions for Drug Users**

- The intervention in the AIDS Community Demonstration Projects aimed to modify attitudes and beliefs about prevention methods among community members by providing models of successful risk-reduction strategies adopted by members of the target population (IDUs, street youth, female sex workers, and MSM). Of the interviewees who participated in this project, 54% were African American and 19% were Latino. The intervention featured role model stories developed from the real-life experiences of community members. Individuals in the intervention communities demonstrated an increased frequency of condom use.
- In an outreach field-site office in Ohio, 381 injection drug users participated in a study comparing a standard and enhanced intervention. Nearly 80% of the participants were African American. The standard intervention consisted of individual pretest counseling, an HIV test, and small group post-test counseling. The enhanced intervention consisted of the standard intervention plus three additional small group (3-5 persons) sessions, led by a counselor. A significantly greater proportion of injection drug users who participated in the enhanced intervention reported safer needle practices than injection drug users in the standard intervention.

## **Examples of Effective Interventions for Heterosexual Adults**

- The Real AIDS Prevention Project (RAPP II) was designed to determine the effects of a community-level intervention, including a media campaign, outreach, and community mobilization, on condom use with main and non-main partners. Participants included 3,725 sexually active women of reproductive age in four matched pairs of inner-city communities. In this group of women, 73% were African American, 20% were Latina, and 7% were of other racial and ethnic groups. Women in the intervention communities reported a greater increase in consistent condom use with non-main partners than women in the comparison communities.
- A study to determine the effects of a small group video-based intervention entitled, Video Opportunities for Innovative Condom Education and Safer Sex (VOICES/VOCES), was conducted in a STD clinic with adult male participants. Of the 2,004 participants, 62% were African American and 38% were Hispanic. Sessions included a 20-minute video and discussion among a group of 3 to 8 men. Men who participated in the intervention had a significantly lower rate of new STD infection than men in the comparison group.

## **Examples of Effective Interventions for Men Who Have Sex with Men**

- The Mpowerment Project looked at the effects of a community-level intervention to reduce HIV risk behaviors among gay men. Of a group of 300 participants, 4% were African American, 7% were Asian or Pacific Islander, 81% were white, and 2% were of other racial and ethnic groups. A core group of young gay men designed the intervention with input from a Community Advisory Board. The multi-component intervention included two types of formal outreach, informal outreach, peer-led small groups and a small publicity campaign. Men who participated in the Empowerment Project reduced their frequency of unprotected anal intercourse significantly more than the men in the comparison community.

- A two-part intervention was delivered to gay male popular opinion leaders as part of the Popular Opinion Leader (POL) project. Of the 1,469 gay men who participated in this project, 9% were African American, 85% were white, 5% were Latino or of other racial and ethnic groups. The first part of the intervention included four 90 minute education sessions related to the epidemiology of HIV, effective and controversial health promotion messages, and real-life conversations and problem solving. In the second part of the intervention, the popular opinion leaders agreed to have conversations about AIDS risk reduction with at least 14 peers in bars. Men from communities that received the intervention reported a significantly greater reduction in unprotected anal intercourse than the men from the comparison communities.

### **Examples of Effective Interventions for Youth**

- Jemmott, et al., conducted research in which African American adolescent males were randomly assigned to receive an AIDS risk-reduction intervention for the purpose of increasing AIDS-related knowledge and lessening problematic attitudes toward risky sexual behavior, or to receive a control intervention on career opportunities. The adolescents receiving the AIDS intervention subsequently had greater AIDS knowledge, less favorable attitudes toward risky sexual behavior, and lower intentions to engage in such behavior than did those in the control intervention. Three-month follow-up data revealed that the adolescents who received the AIDS intervention reported fewer occasions of sexual intercourse, fewer sex partners, greater use of condoms, and a lower incidence of heterosexual anal intercourse than did the other adolescents. These results suggest that interventions that increase knowledge about AIDS and change attitudes toward risky sexual behavior may have promising effects on African American adolescents' risk of HIV infection.
- In the Adolescents Living Safely: Awareness, Attitudes and Actions (3a) Project, a small group intervention was targeted to 312 runaway and homeless youths, of whom 57% were African American, 22% were Hispanic, and 16% were white or of other racial/ethnic groups. The intervention consisted of 10 group sessions on a rotating basis, three times per week, repeated every four to six weeks, and one individual counseling session. Participants in the intervention reduced both the number of unprotected sexual acts and their substance use significantly more than adolescents in the comparison shelters.

It is important to note that some of the studies described here focused specifically on communities of color (an area in need of further attention). Most included research participants from diverse racial/ethnic groups; for these studies, an important area of needed work is sub-sample analysis to gauge the relative effectiveness of these interventions across demographic groups.

### **Findings from NIH Consensus Development Conference**

A 1997 scientific consensus conference sponsored by the National Institutes of Health that reviewed existing data on the effectiveness of HIV behavioral interventions resulted in the following recommendation: "Preventive interventions are effective for reducing behavioral risk for HIV/AIDS and must be widely disseminated" (Interventions to Prevent HIV Risk Behaviors. NIH Consensus Statement 1997, February 11-13;15[2]). The following is excerpted from that report:

Three approaches are particularly effective for risk in drug abuse behavior: needle exchange programs, drug abuse treatment, and outreach programs for drug abusers not enrolled in treatment. Several programs were deemed effective for risky sexual behavior. These programs include (1) information

about HIV/AIDS and (2) building skills to use condoms and to negotiate the interpersonal challenges of safer sex. Effective safer sex programs have been developed for men who have sex with men, for women, and for adolescents.

When we consider the available knowledge from the entire body of literature, we can reach a clear conclusion: Prevention programs significantly reduce HIV risk behaviors. This is true across a variety of risk behaviors and in a variety of populations at risk.

### Do Prevention Programs Reduce Behavioral Risk?

Experts in the field have used different designs for evaluating prevention programs. The most rigorous design used in some areas of research, the randomized controlled trial, has been used in HIV prevention research but is more appropriate for testing some questions than others. For example, evaluating the effects of legislative changes would rarely be possible with randomized research. To draw its conclusions, the panel examined the body of literature in a given area by considering all existing approaches to research, the strength of a given design for addressing a specific question, the number and strength of existing studies, and the convergence of effects.

### Men Who Have Sex With Men

Considerable research has focused on risk reduction in men who have sex with men. Descriptive studies and nonrandomized studies with control groups show positive behavioral effects, as do randomized studies. The studies with random assignment to groups are clustered in two areas: individual interventions delivered in small group settings and programs aimed at changing community norms (e.g., using peer leaders in community settings to deliver programs). These intervention programs focus on information, skills building, self-management, problem solving, and psychological factors such as self-efficacy and intentions. Studies with clearly defined interventions, retention of samples to allow follow-up periods as long as 18 months, and reasonable sample sizes show substantial effects for intervention over minimal intervention or control conditions. More intensive interventions (e.g., more sessions) boost efficacy.

### Heterosexual Transmission

**Adult Women at Risk from Sexual Transmission.** Data from a variety of settings demonstrate the ability to prevent HIV risk behaviors in women. A randomized trial involving a cognitive behavioral intervention aimed at inner-city women with high risk of acquiring HIV through heterosexual contact provides some of the strongest evidence of impact. Three months after intervention, women in the intervention reported a doubling of condom use from 26 percent to 56 percent for all intercourse occasions; no such change occurred for women in the comparison group. A second randomized trial, targeted at pregnant women, shows similar results at a 6-month follow-up. Results from a third randomized study yet to be published show reductions in unprotected sex and sexually transmitted diseases. A study in rural Tanzania involving treatment for sexually transmitted diseases, condom distribution, and health education found more than a 50 percent reduction in HIV seroconversion incidence over a 2-year period in women ages 15-24. Seroconversion also diminished in counseling programs for women attending a clinic in Kigali, Rwanda, and for sex workers in Bombay, India.

*Couples.* There is evidence that consistent and correct condom use reduces HIV seroconversion to nearly zero in both male and female heterosexual partners. Counseling of couples in a European study was associated with large increases in protected sexual behavior.

*Adolescents.* The strongest support for reductions in a broad array of risky sexual behaviors comes from rigorous studies. Five randomized controlled trials used cognitive and behavioral skills training and targeted male and female, African-American, Latino, and European-American adolescents in health clinics and inner-city schools. Studies varied in sample size, and follow-ups were limited to 1 year or less, but results were consistently positive, with outcomes such as condom acquisition, condom use, and reduced number of partners.

### Injecting Drug Users

Prevention for injecting drug users has involved drug abuse treatment in some cases, and outreach focused on both drug use and HIV risk behavior in others. Both approaches have been effective. Programs aimed specifically at treating drug abuse show positive effects on risk behavior and have the additional benefit of affecting drug use. These have shown minimal effects on high-risk sex. Community studies training outreach workers or using an educational media campaign to reduce the use of nonsterile needles show increased protected sexual behavior and slowing of seroconversion rates, along with impressive reductions in drug use.

### Policy and Large-Scale Interventions

As in other areas (e.g., smoking, injury control), policy interventions can remove barriers to protective behavior. In the United States and other countries, such interventions have resulted in dramatic reductions in risk behavior. In Connecticut, for example, a single legislative action legalizing over-the-counter purchase of sterile injection equipment led to an immediate and profound reduction in the sharing of nonsterile needles. A national campaign in Switzerland to promote the use of condoms dramatically reduced risky sexual behavior. Regulations on the use of condoms by sex workers in Thailand also led to fewer unprotected sex acts. The results thus far have been impressive. Given the potential benefit of policy changes, these should be implemented as local circumstances allow and, once implemented, should be evaluated as often and thoroughly as possible.”

### ***Cost-Effectiveness of Interventions***

HIV prevention programs are an outstanding investment of public funds. CDC scientists have developed important tools for estimating the economic impact of HIV prevention programs, taking into consideration the effective combination drug therapies that are now available. The economic model estimates lifetime treatment costs (based on the newest treatment scenarios) and balances those costs against the current national investment in HIV prevention to determine what level of success is needed to save the nation money. The findings indicate that only 3,995 infections must be prevented annually to actually result in cost savings, and only 1,255 infections must be prevented for the investment to be cost-effective. Given recent evidence on the effectiveness of prevention interventions, researchers generally believe that the number of infections actually being prevented greatly exceeds the cost-saving level.

*Implementing a Comprehensive and Effective Community Response  
to HIV/AIDS in Communities of Color*

## **ASSESSING EXISTING SERVICES AND IDENTIFYING UNMET NEEDS**

### ***Overview***

The previous sections of this report provide background on the scope and challenges of addressing the severity of HIV/AIDS in communities of color. Beginning with the epidemiology of the disease in the U.S., its impact on African Americans, Hispanics, American Indians and Alaska Natives, and Asians and Pacific Islanders through interventions and community responses to the epidemic. This section of the report provides an assessment of existing services and programs offered by agencies within the Department of Health and Human Services (DHHS) to address the needs of all communities of color coping with issues relevant to HIV and AIDS and health care disparities. Specifically, this section will review activities and advancements made by the Centers for Disease Control and Prevention (CDC), the Health Resources and Services Administration (HRSA), the National Institutes of Health (NIH), and the Substance Abuse and Mental Health Services Administration (SAMHSA) to counter HIV/AIDS in communities of color and will offer suggestions for future activities.

### ***Inventory of Current HIV/AIDS Activities***

#### **Centers for Disease Control and Prevention (CDC)**

##### **History**

CDC has long recognized the need for prevention programs that are tailored to the needs of racial and ethnic communities. As early as July 1982, CDC experts reported that 37 cases of AIDS-related pneumonia had occurred among African Americans. In 1986, in a special report on AIDS among African Americans and Latinos, CDC reported that Latinos make up more than 1 in 5 cases among women. CDC's major publications, including the Morbidity and Mortality Weekly Report (MMWR) and various newsletters, have regularly featured special reports and articles highlighting such findings. In 1987, a portion of CDC's funding for state and local health departments was specifically designated for prevention programs in African American and other minority communities. In 1988, additional funding was made available for the National and Regional Minority Organizations (NRMO) program. AIDS surveillance data among minorities continued to show the need for additional prevention efforts and, in 1989, minority community-based organizations began receiving direct funding from CDC. All the while, CDC has continued to work to promote awareness of, and support for, HIV prevention by featuring information in numerous scientific presentations, publications, exhibits, and journal articles on the disproportionate impact of HIV among communities of color.

##### **Congressional Black Caucus/Minority HIV/AIDS Initiative**

In 1998, these ongoing prevention efforts were dramatically expanded as a result of the increased funding to enhance the response to HIV/AIDS in racial and ethnic communities. Specifically, increased funding in FY 1999 and FY 2000 has enabled CDC to:

- Support additional community-based organizations for prevention services targeted to communities of color;
- Enhance the capacity of underserved communities to provide HIV prevention services;
- Expand efforts to reduce mother-to-infant HIV transmission;
- Award grants for HIV prevention services to faith-based organizations and organizations specifically working with gay men of color;
- Increase prevention services to reach high-risk minority populations in correctional facilities; and
- Increase HIV testing efforts among individuals at greatest risk for HIV infection.

### ***Community-Based Prevention Projects for African Americans***

Funding for community-based prevention projects for African Americans supports a total of 47 community-based organizations to provide HIV counseling, testing, and referral services, health education and risk reduction interventions, referral and linkages, and coordination and collaboration with health departments and community planning groups.

### ***Community Coalition Development Projects***

Funding for community coalition development projects supports a total of 23 community organizations, including health departments to plan and establish a linked network of HIV, STD, TB, and substance abuse prevention, treatment, and care services in specifically defined, heavily affected communities and communities of color.

### ***Capacity-Building Assistance to African American CBOs***

Funding for capacity building assistance to African American CBOs supports a total of six organizations to provide technical assistance for organizational capacity development, HIV prevention service delivery, HIV prevention community planning, and community capacity and leadership development.

### ***HIV Prevention Projects for Faith-Based Organizations***

Funding for HIV prevention projects for faith-based organizations supports a total of ten organizations to develop HIV and substance abuse prevention curricula and training programs for divinity schools of Historically Black Colleges and Universities (HBCUs), and supports capacity building technical assistance for faith-centered direct HIV prevention service programs.

### ***HIV Community- Based Prevention for U.S. Virgin Islands***

Funding for HIV community- based prevention for U.S. Virgin Islands supports a total of three community-based organizations to provide HIV counseling, testing, and referral services, health education and risk reduction interventions, referral and linkages, and coordination and collaboration with health departments and community planning groups.

### ***Community-Based Prevention Services for Gay Men of Color***

Funding for community-based prevention services for gay men of color supports a total of 34 organizations to provide HIV prevention services to African American, Latino, Asian/Pacific Islander, and American



Indian Alaska Native gay men, and supports a total of seven national, regional, and local organizations providing technical assistance to community-based organizations serving gay men of color.

### ***Corrections Activities***

Funding for corrections activities supports nine projects to link incarcerated populations with community prevention and care services, linked networks of HIV/AIDS, STD, TB, hepatitis, and substance abuse prevention and treatment services and social services, as well as strengthened transitional services between correctional settings and communities.

### ***Early Identification and Patient Education***

Funding for early identification and patient education supports a total of three projects in developing a new and innovative early identification strategies to reach high-risk populations.

### ***Prevention in HIV-infected Persons (PHIP)***

Funding for prevention in HIV-infected persons supports a total of five projects to provide prevention services to organizations addressing the needs of African American HIV-infected persons.

### **Serostatus Approach to Fighting the Epidemic (SAFE)**

Community-based HIV testing efforts are part of a broader CDC effort, the Serostatus Approach to Fighting the Epidemic (SAFE). The SAFE framework focuses on identifying and reaching the growing population of HIV-infected people with quality prevention and other needed services. As with all effective health promotion activities, prevention interventions must be directly targeted to the needs of the individuals or communities for whom they are intended, meaning that approaches that are effective for sero-negative individuals may not be equally effective for those living with HIV.

### **HIV Prevention Community Planning**

The largest share of CDC's support for local prevention programs is channeled through state and local health departments through a process known as HIV prevention community planning. The process brings representatives from all affected communities together with public health officials and other experts to make decisions about funding that are based on the profile of the local epidemic. CDC requires that the membership of the state and community planning groups reflect the epidemic in these jurisdictions and that funding decisions be based on sound science.

### **Capacity Building and Technical Assistance**

Recognizing that lack of infrastructure and resources in communities impedes effective delivery of HIV prevention services to people of color, in 1988 CDC began funding national and regional minority programs to provide consultation, training and other forms of technical assistance (TA) to local community groups. These capacity building activities have steadily increased over time and have evolved to address complex HIV prevention needs. Capacity-building organizations are funded to strengthen community-based organizations and affected communities working to prevent HIV among people of color. In addition, CDC continues to fund and work closely with the Technical Assistance Providers' Network for HIV prevention

community planning. The Network works with community planning groups (CPGs) and CDC project officers to: 1) diagnose and clarify TA needs; 2) identify local, regional and/or national TA providers; 3) arrange for TA providers to deliver assistance; 4) monitor the delivery and effectiveness of TA; and 5) develop tools for use by CPGs and health departments to support community planning.

## **Research**

CDC develops and evaluates both biomedical and behavioral approaches to HIV prevention. The translation of research findings into effective program interventions provides the basis for targeted HIV prevention programs. Currently, CDC is sponsoring the CITY (Community Intervention Trial for Youth) Project, which is a research study in 13 communities across the country targeting young men, ages 15 - 25, who have sex with men. In this study, researchers are evaluating the effectiveness of community-wide programs which use peer health educators, a social marketing campaign, social events, and small group skills-building workshops. As with any new tools for prevention, science must determine what influences people's willingness and ability to use specific methods. CDC behavioral scientists are working on how these prevention methods can and should be balanced with existing prevention options.

## **Health Resources and Services Administration (HRSA)**

*“HRSA’s goal is to have 100% access to high quality health care and 0% disparity in health outcomes for recipients of all HRSA-funded HIV programs. The CARE Act provides one of the only mechanisms where 100% access, 0% disparity can be achieved in the face of this epidemic.”*

Funding support through the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act of 1990 (Public Law 101-381) and the FY 1999 collaboration between the Department of Health and Human Services and the Congressional Black Caucus (CBC), help HRSA and the HIV/AIDS Bureau (HRSA/HAB) work to lessen the burden of HIV and AIDS in African American, Latino, American Indian and Alaska Native, Asian and Pacific Islander communities and other populations of color. In FY 1999 over \$1.4 billion in CARE Act funds supported programs in 50 states, the District of Columbia, Puerto Rico, and U.S. Territories. The Ryan White CARE Act appropriation for FY 2000 is approximately \$1.6 billion. The majority of Ryan White CARE Act funds are used for medical care and treatment. Funding from the Act reaches low income, poor and disenfranchised populations.

In 1998, the Department of Health and Human Services (DHHS), working with the Congressional Black Caucus (CBC), HRSA/HAB's efforts to fight against racial and ethnic disparities in HIV and AIDS care and treatment. The *CBC/DHHS Initiative to Address HIV/AIDS in Racial and Ethnic Minority Communities* added \$17.8 million to the Ryan White CARE Act in FY 1999. Refer to the HRSA/HAB Web site <http://hab.hrsa.gov/> for additional information on the CARE Act.

## **TITLE I FUNDING - Emergency Assistance to EMA's**

Funds support a wide range of community-based services, including outpatient health care, dental care, support services such as case management, home health, housing and transportation assistance, and inpatient case management services. In the first year of CBC/DHHS funding, FY 99, awards were based on EMAs with 30% or more African American and Latino HIV/AIDS cases. In FY 99, CBC/DHHS awards were made to 48 EMAs. For FY 2000, CBC/DHHS Title I grants were awarded on a formula based on the estimated number of living AIDS cases in the EMA. In FY 2000, CBC/DHHS Title I awards reached 51 EMAs and more than 10,000 African Americans and Latinos received new or expanded services.<sup>1</sup> The

goal of these awards is to improve the quality of care and health outcomes for minority populations living with HIV/AIDS, to expand service capacity in communities of color, (i.e. African Americans, Latinos, Native Americans, Native Hawaiians and Pacific Islanders), to assist children orphaned by AIDS, and to expand peer education to individuals with AIDS.

## **TITLE II FUNDING - Formulas Grants and ADAP**

Services supported under Title II include home and community based health care and support services; health insurance coverage; HIV care consortia that assess needs, organize and deliver HIV services; direct health and support services; and drug assistance through the AIDS Drug Assistance Programs (ADAPs). ADAPs provide medication assistance to low-income individuals with HIV disease who have limited or no coverage from private insurance or Medicaid. States project that in FY 2000 approximately 125,800 individuals with HIV disease will access ADAPs. Further, states estimate that in any given month, ADAPs will serve approximately 73,000 people, an increase of 9,000 from the states' 1999 projection of 64,000.

## **TITLE III FUNDING - HIV Early Intervention Services and Primary Medical Services**

In FY 1999 funding support from the CBC Initiative enhanced outreach efforts to target populations eligible for funding under Title III's Early Intervention Services Program (EIS) and to help community health centers, build new capacity for primary care provider organizations to link with CBOs in highly impacted minority communities for the delivery of needed health care services. Because of the CBC support, over 60 CBOs, community health centers and other medical facilities receive funding support.

## **TITLE IV FUNDING - Women, Infants and Children**

Title IV supports comprehensive, community-based, and family-centered services providing a continuum of care for at-risk populations. The majority of clients served by the Title IV programs are from racial and ethnic minority groups—specifically, 48% African American, 30.8% Hispanic, and 9.6% other non-Caucasian.

In FY 1999, Title IV funding supported 48 grants and three special initiatives - the *African American Children's Initiative*, *Grants for Adolescent Services*, and the *REACH Project*. Supplemental funding from the CBC Initiative contributed to the work of the *Ryan White HIV/AIDS Care for Children, Women, Youth, and Families Program*. In FY2000, CBC funding is used to support care and access to care and research for children, women, youth and families affected by HIV/AIDS. Funds were distributed to 16 Ryan White CARE Act Title IV grantees currently funded under Title IV. Supplemental funding to increase the number of minority children receiving services through Ryan White CARE Act Title IV programs reached a total of 53 state and local health departments, community health centers and hospitals.

## **Programs Funded Under Part F**

### Special Projects of National Significance (SPNS)

The SPNS Program funds the development and evaluation of service delivery models for reaching vulnerable populations, improving health outcomes, and responding to changes in the health care environment. Currently there are 27 SPNS grants and 87 SPNS projects under the SPNS Cooperative Agreements Initiative. Over the past five years, seventeen SPNS grantees report serving over 4,800 people. Examples of projects supported by the SPNS Cooperative Agreement Initiative include – *HIV/AIDS Demonstration Projects for Incarcerated Individuals within Correctional Settings and the Community*; *Behavioral Intervention Research Addressing Primary and Secondary Prevention Needs of HIV-Seropositive Injection Drug Users*; *U.S. - Mexico Border Initiative*; and the *Palliative Care and Support Care Initiative*.

### Additional Contributions of the CBC/DHHS Initiative to SPNS Programs

In FY 1999 CBC Initiative funding established the “Integrated Services Through Ryan White Special Programs of National Significance.” The project’s goal is the design, development and evaluation of models of care that (a) target African American and Hispanic communities in Los Angeles, (b) can be replicated in other similar localities, and (c) address the formal linkage and integration of HIV ambulatory medical care and mental health, substance abuse treatment and/or other critical HIV services.

### **HIV/AIDS Education and Training**

As HIV/AIDS patient care has become more complex, the need for AIDS education and training has become acute. It is of particular concern for those providing HIV/AIDS care and treatment to communities of color that are disproportionately affected by the disease. The HRSA HIV/AIDS Bureau addresses the growing need for provider education on HIV/AIDS through the *AIDS Education and Training Centers (AETCs)*, the *National Minority AIDS Education and Training Center (NMAETC)*, *Targeted Provider Education Demonstration Program (TPED)*, the *National Resource Center (NRC)*, and the *AETC National HIV/AIDS Telephone Hotline*.

### AIDS Education and Training Centers

The HRSA/HAB AIDS Education and Training Centers (AETC) network of 17 regional centers and 75 associated sites, conducts targeted, multi-disciplinary education and training programs across the nation. The primary objective of the AETCs is training those in primary health care (physicians, nurses, and dentists), with a special emphasis, on training minority health care providers serving populations of color.

### National Minority AIDS Education and Training Center (NMAETC)

In FY 1999, through a coalition of Historically Black Colleges and Universities (HBCUs), funding from the CBC Initiative helped establish a National Minority AIDS Education and Training Center (NMAETC). Headquartered at Howard University in Washington, D.C., with links to the Charles R. Drew University, Meharry Medical College, Morehouse School of Medicine, the University of Maryland at College Park, and IMANI in Dallas Texas, the NMAETC focuses on clinical training, adherence to therapy, cultural competency, management of HIV complications, anti-retroviral management, and issues that effect hard-to-reach populations.

### Targeted Provider Education Demonstration Program (TPED)

In October 1999, HRSA awarded nine Targeted Provider Education Demonstration (TPED) grants to support HIV/AIDS education and training for health and support services providers working in racial and ethnic minority communities highly impacted by HIV/AIDS. The specialized training developed through the TPED Program prepares providers to address the growing health care needs of people of color living with HIV/AIDS. Providers targeted for the TPEDs include case managers, peer counselors, mental health professionals, social workers, substance abuse treatment providers, outreach workers, day care workers, treatment educators, dieticians, prison health providers, discharge planners, program administrators, home health care workers, and other providers involved in health and support services.

### National Resource Center

The National Resource Center (NRC) is established to support the AETCs, the National Minority AETC (NMAETC), the Targeted Provider Education Demonstration Program (TPED), and other similar, federally funded programs. The NRC serves as a mechanism for review and evaluation of the variety of professional and patient education materials currently in use by the AETC Program. The NRC disseminates information on the most recent advances in treatment and coordinates the development of training materials on HIV and AIDS.

### AETC National HIV/AIDS Telephone Hotline

Under the AETC National HIV/AIDS Telephone Hotline Program, two national telephone hotlines are funded: 1) a hotline to provide information to providers on the appropriate treatment of people with HIV disease; and 2) a post exposure prophylaxis hotline. The Hotline targets Hispanic, African American, and other minority clinicians. The grants also facilitate the dissemination of information to enhance and support the use of hotline services by minority providers, including Spanish-speaking providers.

### **HIV/AIDS Dental Reimbursement Program**

Prevention and treatment of oral health problems common among HIV-positive individuals are crucial for maintaining good nutrition. The HIV/AIDS Dental Reimbursement Program offsets the cost of uncompensated HIV care in teaching institutions, improving access to oral health care, and ensures that dental students and residents are trained to care for persons living with HIV disease. In 1998, the Dental Reimbursement Program funded 101 dental institutions. These funds helped provide care to over 66,000 individuals.

### **Additional HRSA/HAB Services to Populations of Color**

#### HIV/AIDS Peer Treatment/Advocacy Training Institute at USC

In FY 2000 the HIV/AIDS Peer Treatment/Advocacy Training Institute was established at the University of Southern California (USC) to provide high quality training to HIV/AIDS peer educators serving communities of color disproportionately affected by HIV/AIDS.

#### Healthy Start

The Healthy Start project expands HIV and AIDS-related activities for African American and other racial and ethnic minority women of childbearing age in communities identified as Healthy Start communities. In collaboration with the Bureau for Primary Health, activities of this program include outreach to bring women into care, and screening and counseling on HIV/AIDS and substance abuse. FY 1999 funding from the CBC Initiative supports 30 existing Healthy Start grantees.

### **National Institutes of Health (NIH)**

The National Institutes of Health (NIH) supports a comprehensive portfolio of biomedical and behavioral research aimed at preventing, treating, and controlling HIV infection and its sequella in minority communities. Half of the total NIH AIDS research budget is devoted to basic research that benefits HIV-infected adults and children of all racial and ethnic populations. The remaining portion of the budget is invested in more clinically oriented research. Of that portion, NIH invested an additional \$266 million in FY 1996 for research focusing specifically on AIDS in minority populations. In FY 1997 that sum increased to approximately \$278 million. In FY 1998, more than \$300 million was devoted to research targeting minorities; and in FY 1999, NIH plans to spend more than \$323 million.

NIH has established programs and policies specifically designed to recruit individuals from underrepresented racial and ethnic groups into research careers and to build research infrastructure in minority institutions. These programs provide training and research opportunities across the continuum from those for high school students to those for independent investigators. NIH also supports a number of activities with the goal of disseminating research information to healthcare providers serving minority communities as well as to individuals at risk.

Specific information about these initiatives is provided below.

### **Inclusion of Minorities in AIDS Research**

The NIH has implemented a series of guidelines, policies, and programs to ensure that HIV-infected individuals from the most at-risk populations for HIV/AIDS are enrolled and accrued into federally sponsored AIDS clinical trials. In 1994, NIH implemented revised Guidelines on the Inclusion of Women and Minorities in Clinical Research, requiring applicants to address the appropriate inclusion of women and minorities in clinical research. Applications that fail to meet these requirements, as evaluated by peer review, are barred from funding. In such cases, the NIH staff work with the applicants to resolve problems, e.g., by changing the composition of the study populations or identifying projects in the Institutes' portfolios that address similar research objectives and that include women and minorities with which data can be compared.

### **Training of Minorities in AIDS Research**

The NIH recognizes the value of the contributions made by African American health professionals to the conduct of research and research training. A number of NIH programs and policies are specifically designed to recruit individuals from underrepresented racial and ethnic groups into research careers. These programs provide training and research opportunities for high school students all the way up to independent investigators, with the goal of increasing the diversity of the labor pool in all segments of health-related research.

For example, for individuals at the high school, college, graduate, postdoctoral, and investigator levels, the NIH offers Research Supplements for Underrepresented Minorities. Under this program, the principal investigator on a currently funded research project can request an administrative supplement to support the salary of an individual from an underrepresented group who wishes to participate in the ongoing research.

### **Minority Participation in Research Planning and Priority Setting**

OAR includes minority representatives in all AIDS research advisory groups, and the OAR Advisory Council, which provides overall guidance on the scientific direction of the NIH AIDS research program, includes 7 minority members out of the total 18 members. In addition, the OAR research planning groups, which develop the annual AIDS research plan and set scientific priorities, also include minority representatives. These groups have been specifically charged with ensuring that the plan appropriately addresses the needs in minority communities.

### **New NIH AIDS Research Priorities**

Under its newly appointed Director, Neal Nathanson, OAR has adopted a new vision that is directly focused on the epicenters of the AIDS epidemic, including the multiple epidemics in minority communities. This vision, which we have termed "intervention research," gives priority to research that will generate the products and methods required to control the epidemic. Specific priorities include vaccine development, microbicides and other female-controlled interventions, behavioral intervention, interruption of perinatal transmission, immune

reconstitution, and simpler and less expensive antiretroviral treatment regimens. This strategy focuses on the salient problems confronting African American and other minority populations, as well as the medically indigent, homeless, and drug-using groups. The key priorities are prevention of transmission, prevention of disease progression, and prevention of mortality.

## **Research on Issues of Concern to Communities of Color**

### **Population-Specific Interventions**

A number of NIH Institutes, including the National Institute of Mental Health (NIMH), National Institute on Drug Abuse (NIDA), National Institute of Child Health and Human Development (NICHD), National Institute of Nursing Research (NINR), and National Institute of Allergy and Infectious Diseases (NIAID), currently fund a broad array of basic and intervention studies with specific focus on African-American populations. Additional studies are in the planning stages. For example, NIMH supports intervention studies involving African American women in public housing units, mothers and sons, adolescent males, gay men, and families. NIDA supports ethnographic and intervention studies focused on African American male and female drug users, including IDUs and crack cocaine users. NIAID is currently planning an intervention trial focusing on HIV prevention among crack-using African American women. These studies generally are supported through usual NIH grant mechanisms, and some have received special OAR HIV Prevention Science Initiative funds or other supplements.

**Natural History and Epidemiology Research:** NIH conducts studies to examine the transmission of HIV, the progression of HIV-related disease (including the occurrence of opportunistic infections [OIs]), the development of malignancies, the incidence of neurological and neurobehavioral dysfunction, the occurrence of oral manifestations, and the development of other sequella. Ethnic and racially diverse cohorts of HIV-infected individuals and HIV-uninfected individuals at risk of infection are followed in clinical epidemiology studies at domestic and international sites. By maintaining this diversity, data obtained from such studies will have validity for all communities impacted by HIV infection. Examples of studies include:

**AIDS Clinical Trials Infrastructures in Minority Institutions:** The AIDS Clinical Trials Infrastructures in Minority Institutions are supported by NIH to enhance HIV clinical research performed at minority institutions. This program enhances the training and number of minority investigators involved in ACTG research and the number of minority participants in clinical studies. NIH funds the Research Centers in Minority Institutions to support the infrastructure to conduct biomedical research at minority institutions.

**HBCUs:** NIH outreach programs provide training to health professionals affiliated with Historically Black Colleges and Universities (HBCUs) in the use of electronic information resources so that this information is readily available for health professionals working closely with HIV-affected communities.

## **Participation of People of Color in NIH-Sponsored Research**

**Annual AIDS Research Plan:** The NIH's commitment and priority of enrolling HIV-infected individuals from at-risk populations into AIDS clinical trials is underscored in the NIH Plan for HIV-Related Research, which states: "It is critical that the participation of specific populations in NIH-funded clinical trials reflect the changing demographics of HIV infection and AIDS, including women, children, adolescents, drug abusers, injection drug users (IDUs), minorities, the urban poor, and individuals residing in rural areas. Recruitment and enrollment of these underrepresented populations is a high priority in NIH-sponsored studies. Whenever possible, interagency collaboration should be fostered to enhance participation of these populations, including provision of ancillary services."

### **Training and Infrastructure**

**Behavioral Research Training.** NIH supports a program at the Center for AIDS Prevention Studies (CAPS), University of California, San Francisco, titled "Collaborative HIV Prevention in Ethnic Minority Communities." As part of that program, CAPS supports about eight minority scholars in behavioral and social research to spend two summers at the Center to work with mentors and to further develop research, publication, and grant-writing skills. In 1998, four of the eight scholars were African American and focused on issues of HIV prevention and service delivery among African American communities (including the development of Afrocentric models). **International Training.** NIH began a new initiative in FY 1997 designed to provide high-quality overseas research training experience for U.S. pre- and postdoctoral research investigators with a special emphasis on the participation of minority scientists. This program should result in an increase in the number of minority investigators in all areas of basic and clinical research, including AIDS-related studies.

Many NIH Institutes have additional training programs. For example, NIDA, has implemented a number of programs to encourage African American and other ethnic minority students and scholars to pursue careers in drug abuse research. The following initiatives have been established to increase the participation of African Americans and other ethnic minorities in NIDA's research program. None of these initiatives are specifically focused on AIDS research; however, individuals interested in AIDS research may seek support through these programs.

**Research Supplements for Underrepresented Minorities Program.** This program has been utilized to train ethnic minorities to conduct drug abuse research. A number of grants have been supplemented to support training for African American scholars, many of who have been involved in NIDA's AIDS research grant program. Funds awarded through this program may be used to support salaries, tuition, travel, and supplies for recipients.

**The Historically Black Colleges and Universities Research Scholars Award Program.** This RFA was designed to assist HBCUs to develop a research infrastructure and program involving faculty and students. This grant program, funded at the end of FY 1998, allows HBCUs to recruit an experienced research scientist to carry out a drug abuse research program and to train faculty and students. Funds are available through this program to conduct research and enhance the research capacity of the university.



### **Technical Assistance to Historically Black Colleges and Universities Program**

A contract was awarded to Howard University to provide technical assistance to faculty and staff at HBCUs to increase their research readiness and to encourage their pursuit of careers in drug abuse research. A number of drug abuse research applications have been developed under this program. HBCU Drug Abuse Research Infrastructure Building Program. A contract was awarded to Howard University to strengthen its drug abuse research infrastructure and train faculty and students for careers in drug abuse research. AIDS research was one of several subject areas emphasized by the University. Several drug abuse research applications have been developed by Howard University faculty members under this program.

### **Dissemination of Research Information to Minority Communities**

The NIH Office of AIDS Research supports a number of activities with the goal of disseminating research information to health care providers serving minority communities as well as to individuals at risk. These programs are sponsored in collaboration with national and local community-based organizations serving minority communities:

**Regional Meetings:** OAR sponsors a series of regional information dissemination programs to bring current research information to community health care professionals, particularly in minority communities and to communities with the least access to information. Meetings have been targeted to Latino, Native American, and African American communities. Other conferences have focused on issues relating to women.

**Community Forums:** OAR sponsors a community forum program designed to bring research information to the public and communities at risk. A series of scientific meetings, featuring nationally recognized researchers, have been held around the country in collaboration with national and local HIV/AIDS community organizations.

**Collaborations:** OAR sponsors collaborative projects with national community organizations. For example, through an ongoing collaboration with the National Minority AIDS Council (NMAC), OAR is conducting an AIDS Research Institute at the U.S. Conference on AIDS, the largest meeting of minority health care providers and the AIDS-affected community. OAR also is planning to work with the National Medical Association to develop regional outreach activities in association with the Office of Research on Minority Health and the Office of Research on Women's Health.

**National Minority AIDS Council:** In collaboration with NMAC, OAR is collaborating on information dissemination projects that include Internet access to PHS conferences and presentations, AIDS treatment publications targeted to minority communities, and exhibiting of NIH AIDS research information at local and national minority AIDS meetings and conferences.

### **Substance Abuse and Mental Health Services Administration (SAMHSA)**

Since its inception, SAMHSA has supported HIV/AIDS-related activities through its Centers. SAMHSA's Center for Mental Health Services (CMHS) supports a portfolio of projects designed to educate and train traditional and non-traditional mental health care providers to address the mental health needs of HIV-infected persons and those at risk for HIV infection. Since October 1992, more than 64,000 mental health care providers have received specialized training supported by the CMHS program.

SAMHSA is increasingly involved in addressing the interconnected epidemics of substance abuse and HIV/AIDS. In August 1996, SAMHSA, along with other Federal agencies and national organizations, co-sponsored a forum to bring substance abuse and HIV/AIDS policy makers, and service providers together to improve collaboration and integration of substance abuse and HIV prevention. In addition, SAMHSA's Office on AIDS convened a group of experts from the field to assist in the development of effective plans to ensure that substance abuse prevention and treatment, and mental health are fully integrated with HIV/AIDS prevention strategies and to recommend Knowledge Development and Application (KDA) study questions in the area of HIV/AIDS as it relates to substance abuse prevention and treatment, and mental health. In 1997, SAMHSA co-sponsored national HIV/AIDS conferences, i.e., the Latino Lesbian and Gay Organization Conference, the United States Conference on AIDS, and Men Who Have Sex With Men Conference.

In 1998, SAMHSA developed an interagency agreement to fund the National Association of State and Territorial AIDS Directors (NASTAD) to collect and develop informational data on how the states are collaborating around issues relating to HIV/AIDS and substance abuse. Because the majority of the AIDS cases among African American women and children are directly or indirectly attributable to alcohol and other drug use, SAMHSA entered an interagency agreement to fund the National Minority AIDS Council (NMAC) to develop forums to provide a unique opportunity to gather relevant data to assist SAMHSA policy and program staff in developing future strategies to address HIV/AIDS and women-related issues. The SAMHSA AIDS Office initiated the development of a strategic plan for SAMHSA's HIV/AIDS activities and programs.

In FY 1999, SAMHSA received funding from for the Congressional Black Caucus Initiative for comprehensive substance treatment and prevention programs for certain minority populations at risk for HIV or living with HIV/AIDS. These include: substance-abusing African American and Latino men (including men who have sex with men), women and young people. The Center for Substance Abuse Treatment and the Center for Substance Abuse Prevention were designated to administer the CBC-funded initiatives. These initiatives are discussed under the listing of CSAT's and CSAP's HIV/AIDS activities and will continue in FY 2000.

In FY 2000, SAMHSA and its Centers will continue to pursue and participate in collaborative efforts with other federal agencies such as the CDC, NIH, HRSA, IHS and HCFA as well as our state partners and national constituency organizations to address the multifaceted needs of substance abusers at high risk for HIV infection or living with HIV disease. SAMHSA will utilize information and data gathered from the CBC initiatives and activities to continue to target activities and linkages to eradicate and minimize substance use and HIV infection in those communities at high risk.

## **Activities**

### **HIV/AIDS High Risk Prevention/Intervention**

**Project SHIELD:** The *HIV/AIDS High-Risk Behavior Prevention/Intervention Model for Young Adults/Adolescents and Women Program* is a collaborative venture aimed at bringing AIDS prevention into the community. Project SHIELD is a multisite effort with the potential to test the efficacy of HIV/AIDS prevention and interventions and generalize the study results to a larger study population. Although the HIV prevention field has traditionally relied on self-reports of risk behaviors as the primary outcome, Project

SHIELD will measure participants' self-reported behavior change, which may be biased, as well as *actually* measure reductions in diseases such as common STDs that are associated with considerable adverse reaction that may facilitate HIV transmission.

## **Activities Receiving Funding from the Congressional Black Caucus Initiative**

### **Targeted Capacity Expansion Cooperative Agreements for Substance Abuse Prevention and HIV Prevention**

These grants to increase community capacity to provide integrated/cross-trained substance abuse prevention and HIV/AIDS prevention services targeted to at-risk African American, Latinos and other racial/ethnic minority youth, and to African American Latinos and other racial/ethnic minority women. Targeted Capacity Expansion programs target service gaps or emerging problems. This program promotes the selection, adoption/adaption, implementation, and evaluation of the effectiveness of integrated substance abuse and HIV/AIDS prevention interventions that are age and language appropriate, culturally adapted, and gender and sexual orientation-specific.

### **A Contract for Developmental Technical Assistance and Staff Development for 30 - 40 Minority Community-Based Organizations**

Funds under this program would be used to support the development of public and domestic private nonprofit and for-profit minority community-based organizations (CBOs) with a range of different developmental needs. CBOs located in Metropolitan Statistical Areas (MAS) with annual AIDS case rates greater than 15 per 100,000 or in States with annual AIDS case rates greater than 10 per 100,000 population will be eligible to apply for a subcontract. Funds are provided to plan, organize, and develop infrastructure. In addition technical assistance would be offered to support strategic planning, business plan development, program design and development, organizational management, human resources and fiscal management and accounting.

### **Targeted Capacity Expansion Program for Substance Abuse Treatment and HIV/AIDS Services**

This program provides grants to enhance and expand substance abuse treatment and services related to HIV/AIDS in African American, Latino and other racial and ethnic minority communities highly affected by the twin epidemics of substance abuse and HIV/AIDS. Grants funded through this program are expected to target women and women with children, adolescents, men who inject drugs, men who have sex with men (MSM), and men and women who have been released from prison. The program seeks to address gaps in substance abuse treatment capacity, and to increase the accessibility and availability of substance abuse treatment and related HIV/AIDS services (including STDs, TB and Hepatitis B and C) for those targeted populations.

### **Community-Based Substance Abuse and HIV/AIDS Outreach Program**

This program supports community-based HIV/AIDS outreach programs in African American, Latino and other ethnic, racial minority communities with high rates of substance abuse and HIV/AIDS. The program is designed to develop CBO outreach projects, funding outreach workers to provide HIV counseling and testing services, health education and risk reduction information, access and referrals to sexually transmitted disease (STD) and tuberculosis (TB) testing, substance abuse treatment, primary care, mental health and medical services for those who are HIV positive, have AIDS, or are at high risk for HIV.

### **CSAT HIV/AIDS Action Grant Program**

The CSAT HIV/AIDS Action Grant Program supports the adoption of specific exemplary practices related to the delivery, integration or organization of HIV/AIDS and substance abuse treatment services or service systems that are focused on serving African American and Latino and other racial and ethnic populations at high risk of substance abuse and HIV. Grants funded through this program target women and women with children, adolescents, men who inject drugs, men who have sex with men (MSM), and men or women who have been released from prison. Specifically, this program is designed to encourage communities to identify and build consensus around exemplary service delivery system practices that are relevant and meet the communities needs, and that can be readily incorporated into service delivery systems.

### ***Recommendations***

Based on this inventory of HIV/AIDS activities currently underway within DHHS, implementation of the following 20 recommendations for enhanced and new activities to further address disparities among communities of color is necessary to make even greater strides toward eliminating these disparities. Some of these recommendations have been adapted from the draft “National Minority HIV Plan,” dated September 1998, developed by the DHHS Office of Minority Health. In addition, these recommendations have been categorized into six broad public health categories which include: 1) program; 2) program evaluation; 3) policy development; 4) research; 5) surveillance and epidemiology; and 6) technical assistance and capacity building.

### **Program**

1. Increase the number of minority community-based organizations (CBOs) and AIDS service organizations (ASOs) that deliver scientifically sound and culturally relevant prevention programs for communities of color and closely coordinate their efforts with HIV prevention community planning.
2. Make funds available for culturally, linguistically, and gender-appropriate HIV prevention programs for persons who inject drugs. Interventions with a strong scientific basis should be emphasized.
3. Increase access to HIV counseling and testing among communities of color and enhance linkages to care, support services, substance abuse treatment, and mental health services.
4. Consider factors such as prevailing poverty and a lack of cultural awareness that might hinder program planning and implementation in communities of color.

### **Program Evaluation**

5. Conduct continuous quality improvement and evaluations of CBOs, ASOs, and Health Departments (including community planning groups) and make adjustments as indicated and needed.

6. Ensure the representation and participation of all racial and ethnic groups and individuals living with HIV and AIDS in the development, implementation, and evaluation of HIV and AIDS programs.
7. Account for all fiscal and human resources for which DHHS and all agencies involved in HIV/AIDS-related services are responsible and identify the direct linkage between the uses of these fiscal and human resources and a reduction in HIV infection and disease.

### **Policy Development**

8. Ensure that clinical guidelines for incarcerated persons living with HIV/AIDS are consistent with nationally accepted disease definitions and evidence-based guidelines in use for the non-incarcerated population. These guidelines should include provisions for an adequate formulary of pharmaceuticals to effectively treat HIV/AIDS and linkages to medical care upon release from prison.
9. Conduct an analysis of the availability of pharmaceutical agents among clients in publicly-funded HIV/AIDS care, and correct any identified barriers to access.
10. Allow tribes to participate in the Ryan White CARE Act planning bodies (consortia and councils) at the state level. Historically, the tribes have been excluded on the belief that all HIV and AIDS services are covered by the Indian Health Service.

### **Research**

11. Expand research efforts on the barriers to effective HIV prevention programs (e.g., homophobia, discrimination, and stigma) and implement programs and policies to directly confront and overcome these barriers.
12. Continue to place a high priority on the development of microbicides and female-controlled barriers as a key element of an overall emphasis on prevention science research. Continue to support the development and evaluation of improved, acceptable, effective, and safe physical and chemical barrier methods including non contraceptive methods to prevent sexual transmission of HIV and STDs, as stated in the NIH Plan for HIV-Related Research. Continue to support Phase I, Phase II and Phase III trials of various topical microbicides, while exploring additional animal models to facilitate and expedite testing.
13. Continue to actively recruit and retain members of racial and ethnic minority communities (in particular women, youth and transgendered persons) to conduct and participate in existing and new clinical treatment trials and vaccine trials. To facilitate this, NIH should develop a centralized database containing demographic information and provide resources to address transportation, interpretation, and translation needs. In particular, the use of community-based research sites will assist with this effort. In populations where there is an under-representation, over-sampling will be necessary. NIH should look for new and improved ways of addressing the need for increased recruitment and retention of members of racial and ethnic minority communities in the research they conduct or sponsor.
14. Continue the promotion and funding of innovative and culturally appropriate research methodologies. Continue to encourage and fund innovative research methodologies to effectively study racial and ethnic minorities.

## **Surveillance and Epidemiology**

15. Ensure accurate reporting of persons of color with HIV/AIDS.
16. Decrease the number of persons reported as “risk not reported or identified.” This is particularly important in Native American and Asian Pacific Islander populations, where the impact of HIV/AIDS is hidden when incidence rates are compared with other populations.
17. Identify all appropriate data sources, national and regional, for subsequent analysis and reporting of the epidemiology of HIV/AIDS in all four racial/ethnic populations.

## **Technical Assistance and Capacity Building**

18. Continue to provide and refine appropriate, intensive technical assistance and capacity building assistance to CBOs and ASOs.
19. Provide more extensive training on parity, inclusion, and representation to Community Planning Group and Planning Council members to ensure that they conduct more extensive outreach to local leaders in communities of color not already involved in community planning.
20. Continue to create capacity for community-based service delivery and infrastructure within communities and community organizations of color. Technical assistance and the flexibility to contract with technical assistance consultants (nationally and locally) should be expanded.

These recommendations reflect only one piece of a national effort needed to eliminate HIV/AIDS health disparities among communities of color. Most of these recommendations reflect changes in or enhancement of activities which fall under the purview of DHHS. However, any movement toward refining or implementing recommendations such as those presented here will require the involvement of other federal agencies, community members, persons who are infected and affected by HIV/AIDS, national organizations, community-based organizations, and state and local representatives. It is also crucial that programs, evaluation activities, policy development, surveillance, and research activities that arise as a result of these recommendations be culturally and linguistically appropriate.

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## ***APPENDICES***

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**APPENDIX A  
GLOSSARY**

<b><u>ACRONYM</u></b>	<b><u>TITLE</u></b>
ACF	Administration for Children and Families
ADAP	AIDS Drug Assistance Program
AETCs	AIDS Education Training Centers
AHRQ	Agency for Healthcare Research and Quality
AMR	ADAP Monthly Report
ASO	AIDS Service Organization
BIA	Bureau of Indian Affairs
BoP	Bureau of Prisons
CAPTs	Centers for the Application of Prevention Technologies
CARE Act	The Ryan White Comprehensive AIDS Resources Emergency Act
CBOs	Community Based Organizations
CDC	Centers for Disease Control and Prevention
CMHS	Center for Mental Health Services
CPG	Community Planning Group
CSAP	Center for Substance Abuse Prevention
CSAT	Center for Substance Abuse Treatment
CSTE	Council of State and Territorial Epidemiologist
DASH	Division of Adolescent and School Health
DHAP	Divisions of HIV/AIDS Prevention

DHHS	U.S. Department of Health and Human Services
DOJ	Department of Justice
DSS	Division of Social Services
FDA	Food and Drug Administration
FY	Fiscal Year - generally the federal fiscal year, October 1-September 30, designated by the calendar year in which the fiscal year begins (i.e., FY98 begun on October 1, 1998)
HAB	HIV/AIDS Bureau
HARS	HIV/AIDS Reporting System
HCFA	Health Care Financing Administration
HOPWA	Housing Opportunities for People with AIDS a HUD initiative
HRSA	Health Resources and Services Administration
HUD	Department of Housing and Urban Development
IDU	Injecting Drug User
IHS	Indian Health Service
IND	Investigational New Drug applications
INS	Immigration and Naturalization Service
KDA	Knowledge Development Application
NAH	National AIDS Hotline
NCHSTP	National Center for HIV/STD/TB Prevention
NIAA	National Institute on Alcohol Abuse and Alcoholism
NIDA	National Institute on Drug Abuse
NIH	National Institute of Health
NIMH	National Institute of Mental Health
NRMO	National/Regional Minority Organization

ONAP	Office of National AIDS Policy, Office of the President
OpDiv	Operating Division (defines federal agencies that carry out program operations)
OSE	Office of Service Evaluation
SAMHSA	Substance Abuse and Mental Health Services Administration
SAPT	Substance Abuse Prevention and Treatment
SPNS	Special Projects of National Significance
TA	Technical Assistance
YSAPI	Youth Substance Abuse Prevention Initiative

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**APPENDIX B**

**INTERNET HYPERLINKS**

For additional information on HIV/AIDS activities of DHHS and its operating agencies, the following internet addresses can be accessed:

Department of Health and Human Services	<a href="http://www.dhhs.gov">http://www.dhhs.gov</a>
Centers for Disease Control and Prevention	<a href="http://www.cdc.gov/hiv/dhap.htm">http://www.cdc.gov/hiv/dhap.htm</a>
Health Resources and Services Administration	<a href="http://hab.hrsa.gov/">http://hab.hrsa.gov/</a>
National Institutes of Health	<a href="http://www.nih.gov/od/oar/index.htm">http://www.nih.gov/od/oar/index.htm</a>
Office of Minority Health	<a href="http://www.omhrc.gov/omh/aids/aidshome_new.htm">http://www.omhrc.gov/omh/aids/aidshome_new.htm</a>
Substance Abuse and Mental Health Services Admin	<a href="http://www.samhsa.gov/">http://www.samhsa.gov/</a>

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**APPENDIX C**

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**APPENDIX D**

**NIH AIDS CLINICAL TRIALS DEMOGRAPHICS - 1999**

	Demographics of NIH AIDS Clinical Trials		Demographics of AIDS Cases		Demographics of New AIDS Cases	
	Number	%	Number	%	Number	%
<b>SEX</b>						
Male	11,920	68.17	609,326	83.09	35,482	76.47
Female	4,816	27.54	124,045	16.91	10,918	23.53
	749	4.28	3	0.00	0	0.00
<b>TOTAL</b>	17,485	100.00	733,374	100.00	46,400	100.00
<b>RACE</b>						
White	7,280	41.64	318,354	43.41	14,813	31.92
Black	6,037	34.53	272,881	37.21	21,900	47.20
Hispanic	3,027	17.31	133,703	18.23	9,021	19.44
Other	338	1.93	7,479	1.02	546	1.18
Unknown	803	4.59	957	.13	120	.26
<b>TOTAL</b>	17,485	100.00	733,374	100.00	46,400	100.00
<b>TYPE</b>						
Adult	13,804		724,656	98.81	46,137	99.43
Pediatric	3,681		8,718	1.19	263	.57
<b>TOTAL</b>	17,485		733,374	100.00	46,400	100.0